

# THE ABANDONED ILLNESS

A report by the Schizophrenia Commission



November 2012

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# WHAT IS THE SCHIZOPHRENIA COMMISSION?

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The Schizophrenia Commission was established in November 2011 by Rethink Mental Illness. The independent Commission was made up of 14 experts who have worked together to review how outcomes for people with schizophrenia and psychosis can be improved and it was chaired by the eminent psychiatrist, Professor Sir Robin Murray.

The Commission ran six formal evidence gathering sessions involving over 80 experts, including people who have lived with schizophrenia or psychosis, family members and carers, health and social care practitioners and researchers. 2,500 people responded to the Commission's survey online. The Commissioners also visited services across England and drew upon relevant published research literature.

They focused, in particular, on the delivery of adult mental health services but did also consider the impact on young people, those within the criminal justice system, the homeless and those with co-morbid problems such as substance misuse as well as the role of prevention and community development for building an emotionally resilient and healthy society.

# FOREWORD

by Professor Sir Robin Murray, FRS

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Imagine suddenly developing an illness in which you are bombarded with voices from forces you cannot see, and stripped of your ability to understand what is real and what is not. You discover that you cannot trust your senses, your mind plays tricks on you, and your family or friends seem part of a conspiracy to harm you. Unless properly treated, these psychotic experiences may destroy your hopes and ambitions, make other people recoil from you, and ultimately cut your life short. Some 220,000 people in England have such psychotic experiences – we probably all know a family who is affected, but the stigma is such that they may be keeping it a secret.

One hundred years after the term “schizophrenia” was coined to describe severe psychosis, the Schizophrenia Commission came together to examine the provision of care for people living with psychotic illness. We are an independent group which took evidence from around the country and heard from several thousand people over 12 months. What we found was a broken and demoralised system that does not deliver the quality of treatment that is needed for people to recover. This is clearly unacceptable in England in the 21st century.

The inadequate care that many people with psychosis receive adds greatly to their distress and worsens the outcomes for what can already be a devastating illness. Most have a period in a psychiatric hospital unit but too many of these wards have become frightening places where the overwhelmed nurses are unable to provide basic care and support. The pressure on staff for increased “throughput” means that medication is prioritised at the

expense of the psychological interventions and social rehabilitation which are also necessary. Furthermore, some wards are so anti-therapeutic that when people relapse and are in need of a period of care and respite, they are unwilling to be admitted voluntarily; so compulsion rates rise.

The problems are not just in the wards. People with psychosis rarely have the chance to choose their psychiatrist and families are not treated as partners in care but have to battle for basic services. People diagnosed as having schizophrenia have poor access to general practitioners and general hospital care; their physical health suffers and their life is shortened by 15 to 20 years. The fragmentation of services means that people who have a recurrence of their psychosis lose the established relationships with professionals they trust, and instead feel shuttled from one team to another as if on a factory production line.

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Sadly, the great innovation of the last 10 years which everyone says works well - the Early Intervention in Psychosis services - are currently being cut. Instead, the obvious question is: why is it that the integrated therapies that work so well in early intervention are not being offered to people throughout the course of their illness?

The poor quality of care offered to people with psychosis is particularly shameful because, in the last two decades, we have made great strides in understanding mental illness. Gone are the ideological disputes of previous years. Research has instead shown that both biological and social factors are involved, and we have learned that a diagnosis of schizophrenia does not predict inevitable decline. As well as harrowing accounts of personal tragedies, the Commission heard from many people who had been helped to recover and go on to live happy and productive lives after one or more psychotic episodes. Good care delivered by kind, compassionate practitioners can make all the difference. Being given hope is central to recovery too - gaining control and being empowered to build self confidence and self esteem. Time and time again we heard of a transformation whereby an apparently downward course was reversed by a nurse, doctor, peer or therapist who took the time to listen and understand.

We welcome the Government's strategy 'No Health without Mental Health' and the recently published implementation framework. There is broad agreement that services and the experience of those with the condition need to change. The cost of schizophrenia and psychosis to society is estimated at nearly £12 billion in England alone. But we are not spending the money wisely and not achieving the results that we could. If schizophrenia is approached with an understanding that substantial recovery is achievable for most people with the illness, instead of the defeatist

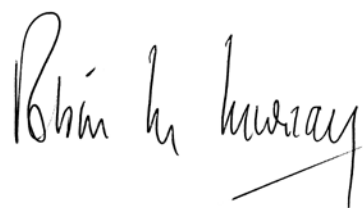
attitude that this is the end of a person's useful life, then we can make a real difference. This is not an expensive fantasy but could lead to an overall saving for the country by turning users of services into contributors to the economy.

What's needed most of all is a change of attitude in each Trust from the community nurse to the Chief Executive. People with psychosis also need to be given the hope that it is perfectly possible to live a fulfilling life after a diagnosis of schizophrenia or psychosis. We have no doubt that this is achievable.

Research has led to an increasing number of effective drugs to choose from and a range of evidence-based psychological treatments. We know much more about 'what works' than we used to and we have seen inspiring examples of recovery-based services in England and learnt of better approaches used in other countries. The committed individuals who went into the mental health profession to improve lives should be helped to do exactly that.

We now need to make sure everyone is offered the treatments that we know work best, delivered with kindness and competence. If we can achieve this, then together we can make the next decade one of increasing recovery for people diagnosed as having schizophrenia or psychosis.

The report which follows sets out some practical steps to make this a reality.



**PROFESSOR SIR ROBIN MURRAY**

on behalf of the Schizophrenia Commission

# SUMMARY

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From our evidence, we concluded that despite the clear progress made in some areas, it is unacceptable that:

- People with severe mental illness such as schizophrenia still die 15-20 years earlier than other citizens.
- Schizophrenia and psychosis cost society £11.8 billion a year but this could be less if we invested in prevention and effective care.
- Increasing numbers of people are having compulsory treatment, in part because of the state of many acute care wards. Levels of coercion have increased year on year and are up by 5% in the last year.
- Too much is spent on secure care - £1.2 billion or 19% of the mental health budget last year - with many people staying too long in expensive units when they are well enough to start back on the route to the community.
- Only 1 in 10 of those who could benefit get access to true CBT (Cognitive Behavioural Therapy) despite it being recommended by NICE (National Institute of Health and Clinical Excellence).
- Only 8% of people with schizophrenia are in employment, yet many more could and would like to work.
- Only 14% of people receiving social care services for a primary mental health need are receiving self-directed support (money to commission their own support to meet identified needs) compared with 43% for all people receiving social care services.
- Families who are carers save the public purse £1.24 billion per year but are not receiving support, and are not treated as partners.
- Service users and family members dare not speak about the condition. 87% of service users report experiences of stigma and discrimination.
- Services for people from African-Caribbean and African backgrounds do not meet their needs well. In 2010 men from these communities spent twice as long in hospital as the average.



We found broad agreement about the changes that need to be made to transform the lives of those with schizophrenia or psychosis and of their families. Encouragingly, we also had support from a range of organisations and practitioners for our approach. We are making 42 detailed recommendations which include:

- A radical overhaul of poor acute care units including better use of alternatives to admission like recovery houses to manage the transition between hospital and community services.
- Greater partnership and shared decision-making with service users - valuing their experiences and making their preferences central to a recovery-focused approach adopted by all services.
- Funding redirected from secure units to strengthen community-based provision and prevention programmes.
- Clarity about who is in charge of delivering care, tackling poor leadership in our services and variations in the quality of care provided.
- Much better prescribing and a right to a second opinion on medication involving, where appropriate, a specialist pharmacist.
- Extending general practitioner training in mental illness to improve support for those with psychosis managed by primary care.
- Extending the popular Early Intervention for Psychosis services (not cutting or diluting).
- Increasing access to psychological therapies in line with NICE guidelines.
- Delivering effective physical health care to people with severe mental illness by improving the training of all mental health staff as well as monitoring the delivery of routine physical health assessment and intervention.
- A stronger focus on prevention including clear warnings about the risks of cannabis.
- Action to address inequalities and meet the needs of all disadvantaged groups.
- A better deal for long-term carers who should be treated as partners.
- Greater use of personal budgets, particularly for those with long-term care needs.
- Psychiatrists must be extremely cautious in making a diagnosis of schizophrenia as it can generate stigma and unwarranted pessimism. The more general term 'psychosis' is preferable, at least in the early stages.

## THE ABANDONED ILLNESS



There are things we can build on. In the last 20 years much progress has been made in understanding schizophrenia and psychosis. There have been many positive developments including the growth of the service user movement, initiatives like crisis resolution teams and early intervention for psychosis services, exercise prescriptions, investment in new IT systems and direct payments. There are now more single sex acute care units with individual rooms, flexible day centre provision and multi-disciplinary team working.

In particular, we have been impressed by accounts of how individual practitioners or whole services have transformed lives through approaches emphasising the potential for recovery and through listening to people's experiences. Being offered hope is crucial, especially when a person with psychosis is at their most unwell. Being involved in decisions over care and treatment genuinely - not in tokenistic ways - is vital.

We also commend the innovative and progressive mental health services that are being delivered in some areas as well as the Government strategy "No Health without Mental Health" which provides a good foundation for building the attitudes and values that we need. We are hopeful that outcomes can be improved for everyone affected by severe mental illness. But it will require a radical overhaul of the system including an integrated approach with health and social services working together, a greater emphasis on patient preferences and a widespread application of flexible and innovative solutions. We do know what works - let's apply it.

We have seen what can be achieved with the approaches to care and treatment in the early intervention in psychosis services which focus on solutions. Today, instead of a life sentence, young people in early intervention services are given hope. They are supported to recover, with many returning to college or the workplace to live an ordinary life like everyone else. We want these outcomes for everyone living



with schizophrenia and psychosis. We will not get them if this approach is dismantled by short term cost cutting restructures.

However, the main message coming from service users and their families is that hope must replace pessimism, the system must give users and carers greater control, and there must be accountability for individual outcomes. Professionals, policy makers and those who have experienced the system must work together in a spirit of respect and co-operation to bring about improvements. Currently there are too many attitudinal and structural barriers hindering change – and this must be tackled.

We want an end to the discrimination faced by people with mental illness. People living with mental illness should be taken as seriously and treated as well as those who are physically ill. Mental illness accounts for 23% of the disease burden in England, but gets only 13% of NHS resources. That imbalance should be corrected.



**No one should claim that we can afford to leave things as they are.**



However, even if resources are not increased immediately, what's available now could be spent much more effectively. In particular, there is a case for a fundamental overhaul of secure provision, reinvesting savings in better community services and preventative programmes. And we could reduce expensive stays in acute units by providing cheaper and more therapeutic 'recovery houses'. We visited a good example of this working in partnership with the local home treatment team. It offered time out from the pressure of living with severe mental illness among staff who valued each individual and their experiences. The place was calm, safe and practical. It sorted out people's accommodation difficulties. We need more recovery houses to keep people out of hospital and help manage transition back into mainstream life on discharge from an acute care unit.

There is clear evidence of serious discrepancies in outcomes and of inadequate care offered to people with schizophrenia and psychosis. This represents a public health crisis which every Health and Wellbeing Board needs to address. The evidence we have heard suggests that every community in England has work to do to improve the experience of people with schizophrenia and psychosis. The system is failing them, their families and the taxpayer. Improvement is possible but it needs leadership across the entire mental health system to make it happen – and that leadership challenge must be firmly grasped.

A number of organisations have already said they would like to work with us to use our recommendations to improve services in their areas, and we hope more will come on board.

No one should claim that we can afford to leave things as they are.

# 100 YEARS ON – WHAT DO WE KNOW?

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Until the 19th century, what was termed madness lay largely in the realm of religion. Then doctors started to take an interest in those regarded as mad and in 1896 the German psychiatrist Emil Kraepelin distinguished between manic-depression, now termed bipolar disorder, and other psychoses. The latter were renamed the group of schizophrenias by Eugene Bleuler in 1911. Nowadays psychosis is the term used to refer to the experience of hallucinations (especially voices) or delusions (false beliefs) or odd behaviour as a result of these. Schizophrenia, however, remains the traditional term for those with more severe psychoses.

For the first half of the 20th century, the outcome for most people diagnosed as having schizophrenia was bleak, and many remained in asylums for decades. However in the 1950s, the first antipsychotic medications were introduced and these, together with more energetic social rehabilitation, enabled many people to leave the mental hospitals. As a result community care was born.

Nowadays, about 45% of people who receive a diagnosis of schizophrenia recover after one or more episodes, but about 20% show unremitting symptoms and disability and the remaining 35% show a mixed pattern with varying periods of remission and relapse (Barbato, 1998).

There is no single cause but rather a range of factors combine to push an individual into psychosis. Genes contribute to vulnerability (Kim et al, 2011; Rees et al, 2011) and children who are born premature or suffer oxygen starvation at birth also have a higher risk.

Heavy abuse of drugs such as amphetamines and cannabis is increasingly considered to be important (Di Forti et al, 2009; Casadio et al, 2011). A range of early socio-psychological adversities such as separation from a parent, being a migrant, growing up in a city, or being persistently bullied or abused, all increase risk of psychosis. Similarly, adverse life events and trauma can precipitate the illness.

All the factors that increase risk of psychosis ultimately impact on brain dopamine levels (Di Forti et al, 2007). For example, not only do recreational drugs increase dopamine levels but so does stress. High brain dopamine levels then lead a person to experience unusual perceptions and give excessive importance or “salience” to commonplace events (Van Os and Kapur, 2009). When people have such overwhelmingly strange experiences they try and find some explanation and this may lead them into delusional thinking.

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Until recently it was thought that there was a clear distinction between people who had psychosis and the general population. However, numerous surveys have shown that up to 15% of the general population will experience hearing voices at some point in their life and 15-20% have regular paranoid thoughts (Tien, 1991; Freeman and Garety, 2006). There is therefore a continuum between those who have no psychotic symptoms and a sizable minority who have mild symptoms that cause them no trouble. A smaller proportion of these people are distressed by their symptoms and consult mental health services and are considered as having psychosis: many of those who are most distressed and disabled by their symptoms meet the conventional criteria for schizophrenia.

Schizophrenia has blurred borders not only with normality but especially with bipolar disorder and with depression. This overlap is the reason why people may be given different diagnoses by different clinicians. Because of the dissatisfaction with the present system of categorical diagnosis, there have been repeated attempts to find an alternative. One is a system based on four symptom dimensions: psychotic symptoms (hallucinations and delusions); affective dysregulation (depression, mania and anxiety); negative symptoms (lack of motivation and withdrawal) and cognitive difficulties (Van Os et al, 2010).

We recognise that many people given the diagnosis of schizophrenia and indeed many working in the services would prefer a less stigmatising alternative to the current term. Indeed, we heard from many who believe that there is so much misconception associated with the term schizophrenia that it has lost its usefulness. We empathise with this view and share the sense of disempowerment resulting from the term's unfortunate and inappropriate connotations. We recognise that it covers a

very broad range of symptoms so diagnosis is not clear-cut and often stigmatising. However, the call to abolish the term schizophrenia is not unanimous. This is both because not everyone feels so negatively about the term and because scientific advances have yet to establish a valid approach to the classification of psychosis to replace the current system. And without greater consensus on an agreed alternative, and a better understanding of causes and remedies, a new term will not in itself deliver an improvement in attitudes.

It is beyond the powers of the Commission to invent or mandate a scientifically valid term that would achieve general agreement. Furthermore, in spite of the efforts of several members of the Commission, it appears that the latest US classification of psychiatric diagnoses – DSM V (Diagnostic and Statistical Manual of Mental Disorders), due to be published in 2013, will recommend keeping the diagnosis though with a welcome new focus on “dimensional assessment” as outlined above using four symptom dimensions. The International Classification of Disease 11th Edition is likely to follow suit.

Nevertheless, we are encouraged by the growing convergence between biological and psychological perspectives on psychosis, illustrated in the expert evidence given to us, and believe this provides an opening for developments which can deliver a better understanding of the causes of psychotic illness and offer new opportunities for developing more effective treatments. The trend to identify different manifestations or dimensions of the illness is likely to accelerate over the coming years as we learn more about the underlying causes. We believe that this holds the key to finding, within the next 5-10 years, a better term or terms to replace schizophrenia.

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**We recommend that psychiatrists are very cautious about making a diagnosis of schizophrenia, in particular after a first episode of psychosis; at that point making such a diagnosis may do more harm than good. The term psychosis, though far from perfect, does not convey the same pessimism and fear.**

The debate about the issue also highlights the importance of an ongoing focus on improving our understanding of the causes of psychotic illnesses.

**We recommend that the National Institute for Health Research and the Medical Research Council develop a new strategy for increasing research investment into the causes and treatment of psychosis with a focus on bringing together biological, psychological and social perspectives.**

There is also much which can be done, here and now, to improve public attitudes towards people diagnosed with schizophrenia and other psychoses. As has been central to rethinking attitudes to other diseases such as cancer, much depends on engendering a realistic but hopeful view of the chance for many people to live a happy and productive life, despite the illness. In recent years there has been progress and Time to Change and other initiatives have made an impact on both attitudes and behaviour.

**We commend the Department of Health, the Big Lottery Fund and Comic Relief for investing in Time to Change ([www.time-to-change.org.uk](http://www.time-to-change.org.uk)) and recommend continued investment in anti-discrimination programmes and other public education initiatives that deliver accurate messages about mental health and mental illness with the aim of changing attitudes and behaviour. These need to address the elements of stigma and discrimination which are specific to people affected by schizophrenia and other psychotic illnesses.**



**“What has struck me from listening to evidence and visiting services is how far we have come since my mum was first diagnosed with schizophrenia in the 1960s. She experienced padded cells, electric shock treatment, strait jackets and debilitating tranquilising medication. My own experiences of services have been better and I now work full time. More is known in how to care and treat schizophrenia but it is not always applied. I want better from the mental health system for everyone. And stigma reduced.”**

Yvonne Stewart-Williams, Member of the Commission

## My experience by Dan

“I have been ill for 15 years. I only found out my diagnosis by chance – when on one admission to hospital the doctor announced from a pile of notes “well it says he has schizophrenia”. I was a bit concerned about this diagnosis but it was good in a way because I finally realised that there was a name for how I felt and it could be treated.

I have been admitted four times to my local hospital and two times to a specialist OCD (Obsessive Compulsive Disorder) unit. The best admission was when they geared you up for leaving hospital feeling inspired that things would get better. I felt a wave of confidence and went back to study for a degree.

Overall hospitals, however, are terrible places. Over the years staff have largely been helpful but they rarely ask you what you want – not that I would know as it’s a difficult question. At its worse my illness makes me very anxious and I worry I will die. It’s hard when staff don’t take your worries seriously. I was convinced I had cancer but they dismissed this and laughed at me which made my anxiety worse because I thought I wouldn’t get treated because I was mental.

Today I am looked after by a CMHT (Community Mental Health Team). My CPN (Community Psychiatric Nurse) visits monthly to check on medication. I have a lady who comes in twice a week to help me look after my flat, and I see my psychiatrist. I recently had a second opinion review which was very positive. I have been on an untold number of medications which is very frustrating – particularly as many of them make you fat. These doctors really listened and took interest in me and we are now changing my medication. They showed me there was an alternative to the doom and gloom.

I want to be more confident, maybe get a job, be a bit more sociable as I am a bit socially phobic. I don’t feel medication does you any good but there is lots of harm coming off so you stay on the tablets for that reason. I am hoping my new medication will be better.”



**Dan’s experience shows that things can get better. I hope our recommendations help mental health practitioners and services to improve the work they do with service users such that even the basic standard of care provides a positive outcome from the start of treatment rather than it having to take years, as it did with Dan. All service users should be able to say they are satisfied and happy with the care they’ve received and that their doctors really listened and took interest.** Shubulade Smith, Member of the Commission





**I feel that the current Early Intervention Psychosis service is the most effective thing available to people experiencing psychosis because they actively promote engagement with clients and support networks.**

**They aim to empower and educate as well as encourage self-management and choice. I feel services as a whole would improve if early intervention principles were undertaken in all aspects of mental health care.**



FAMILY MEMBER

# GETTING HELP EARLY IS CRUCIAL TO GOOD OUTCOMES

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Early intervention is crucial to improving outcomes. The Commission's view is that Early Intervention in Psychosis (EIP) has been the most positive development in mental health services since the beginning of community care. These services are popular with service users and families and there is a clear evidence of their effectiveness. Staff who work in them are positive, committed, they enjoy their work and tend to be well led.

There is a stark contrast in how early intervention services are viewed compared to the rest of the system however. These services are giving people with psychosis hope and their lives back. Obviously this is not the only part of the system where staff work in this way but nowhere else have we seen the constant high standards, recovery ethos, co-production and multi-disciplinary team working. When people move on from EIP outcomes become less certain (Gafoor et al 2010). We want the values and ethos of EIP to spread across the entire mental health system.

## WHAT WE HEARD IN OUR EVIDENCE

**“What I needed was Early Intervention Services. They said: “this is our interpretation, you can attach your own meaning” – it’s important that services emphasise that there are different perspectives.”** Service user

**“Early Intervention teams: They combine skill with speedy intervention (seen within a few days), creativity and a range of interventions that put the patient and their family at the centre of care planning.”** Care coordinator

Early intervention services are valued on account of their ethos and approach. Those giving evidence emphasised the value base of early intervention services – their kindness, hopefulness, care, compassion and focus on recovery. They provide treatment in non-stigmatising settings, seek to maintain social support networks while an individual is unwell, take account of the wider needs of the individual and deliver education as a core part of the service to families, staff and service users.

We were impressed by the robust evidence for their economic effectiveness too. Over a three year period, a high quality Early Intervention in Psychosis service is estimated to save the NHS £15,862 per person with first episode psychosis and the Exchequer £16,663 when compared to standard services.<sup>1</sup> That is a potential £119 million saving for the NHS and £125 million for the Exchequer.

The Commission was concerned at the evidence it heard of plans to cut or reconfigure early intervention services, for example where the label ‘early intervention’ was maintained but where the resources were no longer provided to run in keeping with the original service model. This will increase pressure on more costly acute care services. Given the evidence collected of their popularity and effectiveness, such changes would be highly counter-productive and fly in the face of the needs of people with psychosis.

**“Mental illness is a young person’s problem, yet our services are often least effective with this age group – particularly young adults. Progress has been made with some Early Intervention in Psychosis services but these need developing and expanding not, as is feared, cutting for short-term cost saving.”**

Mental health nurse

The model of early intervention that is so highly valued by practitioners, families and people with lived experience only lasts two to three years. There is an important case for extending the approach and ethos of early intervention teams to other parts of mental health services to ensure that people experiencing second and subsequent episodes of illness receive effective support which addresses the totality of their needs rather than the disjointed care which often seems to be all that is offered.

In short, people with more established illness still need the same person-centred approach with services working together and providing continuity of care and clarity about who to turn to in crisis.

## WHAT NEEDS TO CHANGE?

### Protect existing Early Intervention in Psychosis services

Early intervention services are valued by people who use them, and their families, and have demonstrated their effectiveness in improving outcomes. We want to see increased investment in the approaches adopted by these services and a spread of their values and ethos.

**We recommend that all Clinical Commissioning Groups commission Early Intervention in Psychosis services with sufficient resources to provide fidelity to the service model. It is crucial that the NHS Commissioning Board holds local commissioners to account for this and we recommend that early intervention services are included in the NHS Commissioning Outcomes Framework.**

### Extending the principles of early intervention to other services

We believe there is a very strong case for extending the EIP ethos and approach to services for people experiencing a second or subsequent episode of illness. In fact it should be a priority for local commissioners and providers of mental health services.

**We recommend that Clinical Commissioning Groups commission services to extend the successful principles of early intervention to support people experiencing second and subsequent episodes of psychosis.**

**“We can be really proud of our early intervention services which are popular and have been shown to work. Now we need to build on that success by extending the approach to cover the whole service.”**

Liz Meek, Member of the Commission

1. This report quotes cost data from an accompanying report prepared specifically for the Schizophrenia Commission. All unreferenced cost data is from: Andrews A, Knapp M, Parsonage M, McCrone P (2012) Effective interventions in schizophrenia; the economic case. London School of Economics and Political Science.



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**I work in Early Intervention in Psychosis and see the difference these services make to people's lives. It's not just intervening early that makes the difference.**

**It's about staff who believe in recovery, delivering individualised, high quality care. EIP services improve outcomes, save money and are valued by service users and carers alike. This must be the success story of mental health services.**

”



ALISON BRABBAN  
MEMBER OF THE COMMISSION

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**Our family was propelled into the parallel universe of mental illness some four years ago when my son, then 24, had his first psychotic episode.**

**In the preceding years, I'd had concerns about his state of mind which I expressed many times to the GP. With the wisdom of hindsight, my son should have received treatment much earlier so his chances of recovery would have been much better.**

**So, WHY was the GP so ineffective in intervening to help, WHY was I told: “this really isn't anything I know very much about” and “there really isn't a lot we can do” when the need for early intervention and cooperation between families, doctors and schools is so obvious (with the benefit of hindsight)? Prevention is better than cure.**

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FAMILY MEMBER

# PREVENTION

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Prevention is essential in the front line battle to improve the health of the nation. Public Health England is being established to give a central place to public health and mental health must have a key place in its priorities. The positive thing is there are many foundations to build upon across the country because over the past few years significant progress has been made to develop parenting programmes, school mental health initiatives, anti-discrimination campaigning and community wellbeing projects. We do, however, need to do much more preventative work to improve outcomes for people affected by severe mental illness.

The Commission's view is that we are failing many people who go on to receive a diagnosis of schizophrenia because not enough is done early on to prevent its development. We know the risk factors for developing psychosis, including migration and discrimination, childhood trauma, bereavement or separation in families, and abuse of drugs. However, too little energy or resource is focused on addressing these problems. In 2010 only £3 million (or less than 1%) was allocated to mental health promotion from a total budget direct spend of £5.36 billion (Mental Health Strategies, 2011).

## WHAT WE HEARD IN OUR EVIDENCE

**“Services appear to be directed into managing problems when they occur, rather than for example helping people manage their own lives effectively, or helping them understand their illness and how to live with it, or to access housing, employment and a social life. Time and staffing constraints, and a focus on treatment rather than prevention, is impacting on their ability to lead as normal a life as possible.”** Mental health nurse on a substance use detoxification unit

We heard that there is a good public health and economic case for investing in wellbeing promotion and preventative interventions with young people at risk of developing psychosis. A priority is education about the risks of cannabis use.

The latest research worldwide shows a strong link between taking drugs, especially cannabis and stimulants such as amphetamines or “legal highs”, and the onset of psychosis including schizophrenia. Risks increase the younger regular use of the drug starts (Casadio et al, 2010).

Our respondents confirmed that in many cases problems started with heavy cannabis use, especially of high potency types such as “skunk”, in adolescence. Fortunately consumption has decreased steadily since 2004 (British Crime Survey 2011/2012) but a targeted campaign along the lines of smoking cessation would make a big difference.

**“So much needs to be done to improve the lot of the person with a mental health condition, but for that to happen people would have to change their perceptions of mental health and become more accepting and caring. I was a victim of sexual abuse as a youngster from both sexes soon after the death of my mother. I repressed this and kept it secret for about 15 years. This, along with cannabis use that exacerbated paranoia, contributed in my opinion to my psychosis.”** Service user

Part of the debate around prevention is tackling stigma. People do not seek help early enough when psychosis is developing for fear of being labelled mad and reactions to that label among peers, family and the community. Suspicion over mental health services and what might happen to you is also a factor in delaying seeking help – particularly within ethnic minority communities who fear being misunderstood and wrongly labelled.

We are concerned at the increasing numbers of people treated under section, partly because they delay seeking help until they are at crisis point. Levels of coercion are on the increase too, with a 5% increase in detentions under the Mental Health Act 2010/2011 over the previous year. It’s particularly high for Black African and ‘other’ minority groups where rates are up to two times higher than average.

The use of Community Treatment Orders accounts for most of the increases we have seen over the last three years, with total detention rates up by 17%, 12% and 5% respectively. Involvement of the police, family or friends in the section process can lead to on-going distrust of the services which delays people seeking help still further.

**“There needs to be a lot of education in the community because at the moment it does not care or understand the true nature of the suffering involved in mental illness and this needs to change dramatically. Mental illness chooses you, you don’t choose it.”**  
Family member

We want to see an expansion of preventative programmes to address the causes of triggers to developing schizophrenia and psychosis which occur in childhood. This would include investment in parenting programmes, school mental health and youth mentoring.

Mental health promotion has to cover the entire life cycle too – from birth to old age. While there is a recognition of the importance of prevention in Government strategy, we are concerned about how this will be delivered. There are few evidenced-based preventative programmes and very little mental health research spending goes into prevention or mental health promotion.

In the strategic analysis of UK mental health research spending in 2005, only 2% of the entire budget of £40 million was on prevention and none of this was directly for schizophrenia and psychosis. We have no reason to believe the situation has changed; but it needs to.

The school curriculum does not emphasise mental health first aid and mental wellbeing or prevention either. This should include building emotional resilience, the risk of taking drugs, the pressure of exam stress, the damage of bullying. We heard that the reason for this is the fear of revealing an iceberg of psychological problems which the school is not able to respond to. But someone does have to respond; the individual, their family, the health and social care system and society all need to tackle the consequences of a young person developing psychosis and seeking help too slowly. The pain and disruption as well as the cost are immense.



**“Government and media have played up the risks mentally ill people pose rather than the risks they run. Though this has improved in recent years both still contribute to the stigmatisation of the most vulnerable in society. It must stop.”**

Jeremy Laurance, Member of the Commission

Prevention and promotion are not only relevant for the young. We must also prevent the relapse of acute psychosis and development of multiple problems like addiction, depression, anxiety, heart disease, diabetes and cancer.

Developing self-management strategies, such as those emphasised in the Mental Health Foundation ‘strategies for living’ project several years ago, is essential for managing psychosis and keeping well. Courses to help individuals manage their health and emotions are important, and peer support can be vital in developing coping and healthy living strategies. Advance directives and crisis planning can also assist the management of crisis periods.

People with severe mental illness are at increased risk of developing chronic physical health problems. As covered elsewhere in the report, we must have preventative programmes tackling cigarette smoking, screening programmes, and use of practice nurse-led interventions to promote healthy lifestyles, including exercise programmes. These must build upon a collaborative care model addressing the interface between secondary and primary care.

We also have to look at who is delivering preventative interventions – with potential roles for peer support workers but also the wider primary care family including school nurses, practice nurses, health visitors (whose numbers are all currently in decline).

People with psychosis are also at risk of getting into debt. Currently 1 in 4 people with a mental health problem are struggling with this problem. Indeed research found that people in debt had four times the rate of psychosis compared to the general population (prevalence of 1.6% compared to 0.4%; Jenkins et al, 2009).

Our public health programmes must prioritise mental health in the broadest sense because the consequences of severe mental illness affect all parts of people’s lives – social, cultural, health and wellbeing, economic and spiritual.

## **WHAT NEEDS TO CHANGE?**

### **Investing in prevention**

There is a powerful argument for doing more to address some of the key environmental risk factors which increase the incidence of schizophrenia and psychosis.

**We recommend that Public Health England develops a preventative strategy for psychosis including promoting protective factors for mental wellbeing and reducing risks such as cannabis use in early adolescence. This area needs to be addressed within the Public Health Outcomes Framework.**

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**My experience of hospital was less than desirable. The nurses staffing the ward spent most of their time in their management area, with little or no contact with patients. One patient with obvious severe difficulties was repeatedly verbally abused by the patients and yelled at by the staff for his, at the time, undesirable behaviour.**

**Unsurprisingly after a while he became enraged and frustrated, lashed out, breaking a care worker's nose, and leaving others bruised and battered. This hardly made for a relaxed recovery.**

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# IMPROVING ACUTE MENTAL HEALTH CARE

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Most people with schizophrenia or psychosis will spend time within an acute care or other hospital unit when they are unwell. Acute units form a crucial part of the mental health system and people have a right to expect high quality care and treatment when they need it most.

We are aware of some excellent services which do just that and where anyone would be confident to recommend a friend or family member be treated. However, we are not the first inquiry to be concerned about the number of services which are frightening, un-therapeutic and fail to demonstrate the compassion which should be expected when caring for very vulnerable people. This is unacceptable in the 21st century.

Ensuring good quality acute services are in place must be a top priority for the commissioners and providers of mental health services. It is a scandal when serious failings are found in emergency services that cater for physical conditions, so there should be no difference when it comes to services for those with an acute mental health condition.

In the long term we believe there is scope to make better use of resources, especially if we can achieve the better commissioning of secure care. However, we are very concerned to hear about the pressure to cut acute services in the interest of finding short-term savings. This will undermine good services and further exacerbate the difficulties of others.

## WHAT WE HEARD IN OUR EVIDENCE

At any time a third of people on acute mental health units will have a diagnosis of schizophrenia or other psychotic illnesses. The figure is often much higher in inner city units and amongst patients detained under the Mental Health Act. Over a lifetime, most people with severe mental illness have at least one hospital stay.

Delivering good acute care needs strong leadership and management. It is about delivery of a range of interventions effectively and with kindness and care while assessing and managing complex risks. We heard how some NHS Trusts have invested in improving the physical environment and quality of care on their acute care units, and where services provide respite and calm. We also heard about impressive programmes for improvement such as Star Wards and the Royal College of Psychiatrists' Accreditation for Inpatient Mental Health Services (AIMS) which are helping leaders to change conditions and working practices.

We also heard about examples of good practice from abroad. For example, the Burgholzli Hospital in Zurich, where Bleuler coined the term schizophrenia, provides mentally ill people with facilities which give

each patient access to beautiful gardens, exercise facilities, and, in most cases, single rooms with showers. In addition each unit has a “therapeutic” dog relieving tension and bringing comfort to people.

It is not unreasonable to expect that such examples of good care and treatment should be the norm for people who are acutely unwell with a serious psychotic condition such as schizophrenia. Sadly this is not the case on far too many occasions.

In our evidence we heard of many acute units which were stressful, chaotic and scary places. No one seemed to be in charge. Violence, theft and sexual harassment against staff and patients, boredom, poor environments, lack of activity or staff-patient engagement were highlighted as criticisms. Un-therapeutic services, characterised by a sense of hopelessness, staff who do not engage with patients, together with bleak décor and furnishings, can lead to people reacting badly to their hospitalisation. Indeed, when people later relapse, the memory of being in hospital leads to people refusing admission and being “sectioned”.

Such services have difficulty maintaining regular staff and have to rely on locum bank nurses. The pervasive gloom that such units spread has an adverse effect not only on patients but also on the recruitment of nurses, social workers and doctors into mental health services.

There are also issues of capacity. Occupancy rates are known to be high, often above the 85% recommendation, and some Trusts have cut back their acute care units so much that they now have to send patients away to poor quality provision as far as 80 miles away. Not only is it distressing for people to be shuttled about in this way but it is also very expensive.

Improving acute and crisis care was the single most important improvement in the services wanted by respondents to our survey. 35% of people with lived experience of illness and 41% of practitioners said it was a priority for acute care settings to be reformed.

We echo many of the findings from Mind’s Listening to Experience report on acute and crisis care (Mind, 2011)<sup>2</sup> and their call for services to be built upon principles of humanity, choice and control, commissioning on the basis of people’s need and reducing the medical emphasis in acute care.

This must be a major issue for commissioners and providers of mental health services and both must satisfy themselves that local provision passes the “friends and family” test: if you had a relative with psychosis or schizophrenia, would you want them treated in this unit?

### **The key challenges for improving acute services are:**

- Acute services need to be places of safety and rehabilitation that people choose to be in when they are ill, rather than choose to avoid. An individual’s long-term engagement with the mental health system may be affected by negative experiences of acute care.
- People are highly distressed on hospital wards, yet we have a service model based upon managing crisis not preventative care, respite and calm.
- People have multiple problems - mental health, addiction, homelessness, unemployment, physical ill-health, trauma, relationship breakdown, debt - which all need to be addressed.
- Coercion (being assessed and treated by force) should be minimised, despite it being essential in some cases. Over 50% of violent incidents can be managed with verbal de-escalation alone and early intervention, with a good understanding of the antecedents of aggressive behaviour, will reduce the need for coercion and provide a more satisfactory experience for the service user (Shepherd et al, 1999; Herlihy et al, 2010).
- Advance directives (in which a person while well says what they would like done and who they would like involved if they relapse) should be generally used. They have been shown to reduce use of treatment under compulsion and also to reduce costs. (Henderson et al, 2004).

2. Information on Listening to Experience and the Mind crisis care campaign: [http://www.mind.org.uk/campaigns\\_and\\_issues/current\\_campaigns/care\\_in\\_crisis](http://www.mind.org.uk/campaigns_and_issues/current_campaigns/care_in_crisis)



- There is a disproportionately high number of people from disadvantaged groups, such as black groups, within acute care settings who are highly dissatisfied with the care provided.
- The constant stress of dealing with very disturbed people leads nurses who started their careers as idealistic enthusiasts to burn-out. There are high rates of sickness absence and poor opportunities for them to develop their skills. We heard that temporary staff often hide in offices, shy away from talking to patients and even appear to lack essential caring qualities.
- Physical health problems are not addressed and there is a lack of therapy or exercise and little for people to do.

Over the last 10 years there has been significant investment in crisis and home treatment teams and in the development of community based alternatives to admission such as crisis houses. The Commission supports this development and considers that, where they work well, such services can provide an effective alternative to hospital admission which is popular with service users and families (Lloyd-Evans et al, 2010).

Hospital care accounts for 38% of the total health and social care costs associated with people affected by schizophrenia and psychosis, with a significant proportion spent in secure care settings. In 2010/2011, £1.2 billion or 19% of the direct services mental health budget for adults of working age was spent on secure and high dependency services.

While clearly recognising the need for provision for people who may be a risk to themselves or others, we believe there is scope for rationalising provision and releasing savings to reinvest in community based provision. There are also large variations in the uses of acute beds and particularly in the average length of stay across NHS Trusts. There may be scope to make better use of acute care resources by investing in community based alternatives to admission.

The Commission is aware that recently there have been high profile deaths of mentally ill people as a result of prolonged restraint by the police and police use of Taser. The Commission strongly advises against the use of this type of force.

We commend the reduction in prolonged prone restraint by psychiatric services over the years since the Rocky Bennett inquiry (Blofeld, 2003), but are mindful that not all units are aware of the importance of this. Physical restraint, if needed, should mainly be to transfer an individual to a safer environment, for example their room, intensive care areas or supervised confinement.

Although mechanical restraints are widely used in Europe and North America, the Commission strongly condemns their use and believes that the emphasis should be on less rather than more coercive techniques.

## WHAT NEEDS TO CHANGE?

### Ensuring all acute and crisis care passes the friends and family test

We must address concerns about existing acute care as a priority. It is crucial that Boards and senior managers in Mental Health Trusts have a clear understanding of the quality of the units they are responsible for, based on regular visits and direct feedback from the people who use those services and their families.

Commissioners must take the responsibility for ensuring they are making sufficient investment in this area, meeting the local need, and providing a good quality of care and treatment.

**A radical overhaul of acute care is needed and only units which patients would recommend to family and friends should be seen as “good enough”. We recommend that the NHS Commissioning Board introduces as soon as possible a “friends and family” test for acute mental health units which reflects the issues of concern highlighted in this report and in previous work such as Mind’s report on acute and crisis care “Listening to Experience”. We recommend that the Department of Health asks the CQC to reinstate its annual survey of the standards of inpatient care to provide an independent view on the quality of services.**

### Alternatives to Admission

We support the development of a range of community based alternatives, building on the success of the crisis house model often run by voluntary sector providers. Such services can provide intensive social support and refuge.

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Recovery houses can offer an alternative to an acute admission or be a half-way house back to the community after time on an acute ward.

These services need to work with acute care units and with crisis and home treatment teams and to share information effectively about risk and needs. Sadly some Trusts are closing such units in a search for cost savings. We are, however, confident that investment in such services could be supported through savings generated by better use of acute care beds and a reduction in out of area placements. Alternative providers such as voluntary organisations and charitable housing associations should be involved in discussions about expanding this provision.

**We recommend that Clinical Commissioning Groups and providers explore alternatives to admission as part of their plans for the development of acute care and crisis services.**

#### Secure care

There is a place for secure provision for people who may be a risk to themselves or others. However current provision costs £1.2 billion or 19% of the entire adult mental health budget and we are concerned at how this is being used.

As highlighted by the Centre for Mental

Health, there appears to be no clear criteria for different categories of secure provision and a lack of effective care pathways for people in the secure system.

People stay too long in very expensive and often unsuitable provision. The concentration of commissioning responsibility being placed with the NHS Commissioning Board provides an opportunity to carry out a root and branch review of secure care.

We think that the preoccupation with risk (important though this is) has forced psychiatrists into relying increasingly on compulsion: too many people end up unnecessarily in Forensic Units at great expense and to the great detriment of general mental health services (Wilson et al 2011).

We believe that it should be possible in the next five years to identify substantial savings which should be reinvested in improving local acute care and strengthening community based provision.

**We recommend that the Department of Health, with involvement from the Ministry of Justice, requires the NHS Commissioning Board to develop a national commissioning strategy for secure care with the aim of rationalising definitions of security and establishing recovery-focused care pathways through secure care. Savings identified as a result of this exercise should be reinvested in strengthening community based provision.**



**It is such a missed opportunity to get people's lives back on track. No-one is happy about the state of acute care units – the staff, the patients and the families hate them.**



Liz Meek, Member of the Commission

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**The most useful thing is medication, and not just bunging someone on it and leaving them; monitoring it, changing it, adjusting it as needed to provide optimum stability with minimum medication and minimum unwanted side effects.**

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# ANTIPSYCHOTIC MEDICATION IS CENTRAL TO TREATMENT BUT CURRENT PRACTICE IS OFTEN INADEQUATE

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It is clear from our work that antipsychotic medication is the cornerstone of treatment for schizophrenia and psychosis but the existing medication often has unpleasant side effects. Poor prescribing practice must be eliminated and shared decision-making must form the cornerstone of practice. People should be properly involved in decisions about the medication they take.

## WHAT WE HEARD IN OUR EVIDENCE

When asked in our survey what was the single most effective support for managing schizophrenia and psychosis, most people said medication. When asked what treatment was most helpful, again medication was rated most highly by 73% of our 2,475 respondents. It is the foundation upon which personal recovery is built for many. But it is not without severe limitations and problems.

We heard much about the negative consequences of medication, in particular:

- The risks to a person's physical health from long-term poorly-prescribed medication include weight gain, diabetes and heart disease.
- The impact of side effects on a person's quality of life. For many this included drowsiness, sexual dysfunction and restlessness. 53% of respondents felt the side effects of medication were the key treatment problem.
- The side effects can directly affect a person's willingness to take medication and may cause them to come off it abruptly, leading to relapse.
- Most people come off medication after a few years to see if they can manage without or in reaction to the side effects.

The Commission found that, despite some evidence of improvements driven by initiatives such as the Prescribing Observatory for Mental Health Audit (POMH-UK), there are still persistent deficiencies in prescribing practices, including too many people with drugs prescribed above the maximum prescribing guideline limits.

We were also concerned that a specialised medication like clozapine was not offered to everyone who might benefit from it. When people are first diagnosed, about 80-95% respond to the first or second antipsychotic that's given to them and only 5% are found to be resistant to treatment (Agid et al, 2007).

Later in the illness the proportion of people who do not find appropriate drug treatments is difficult to estimate but may be up to 30%, of whom 60% would respond to clozapine if offered (Meltzer et al, 1989). Some people with schizophrenia and psychosis live a difficult life haunted by continuous voices criticising their every action and by paranoid fears that other people are out to get them. The drug clozapine has been proven to benefit this group dramatically but is prescribed to too few and often only after many years of needless suffering.

Many service users feel they are not consulted properly on the pros and cons of the various medications that are available. People feel experimented on while different drugs are tried to establish an appropriate dose and medication type. Many are not offered other types of medication either, like mood stabilisers or antidepressants, that could help them reduce depression and anxiety and allow them to decrease their antipsychotic medication.

**“For a long while I felt like doctors were just using me as a guinea pig and just trying different drugs because they didn't know what to do with me.”** Service user

**“I would like to see more clinical pharmacists employed by mental health services to support service users and carers in the best use of their medication to increase adherence, safety and recovery.”** Chief pharmacist for Mental Health Trust

We heard about how some people manage their own medication to maximise its benefits and minimise side effects. Too many doctors believe that people with a psychotic illness, especially if diagnosed with schizophrenia, must be on antipsychotics for life. The evidence is that some people may have to stay on medication but others can gradually reduce and eventually come off their antipsychotic.

This is best tried under close medical supervision. People try to come off antipsychotic medication too rapidly and by themselves, and may relapse as a consequence. For these reasons, the Commission feels strongly that prescribing must become more personalised.

Finally, while most people who have an acute psychotic episode benefit from antipsychotics in the short term, there is much less certainty about how long people should remain on these medications. The Commission heard from people with a diagnosis of schizophrenia who had successfully come off antipsychotic medication. The Commission feels that there should be continuing dialogue about whether it is necessary to keep on taking antipsychotics and in what dose. More help should be provided to those who wish to decrease their dose and if this is successful to try to manage without medication; the latter needs to be done with close monitoring in case it leads to relapse.

**“I was told I'd never come off medication, but I did and remained well for nine years ... some people can be well and drug free, at least for some time.”** Service user

## WHAT NEEDS TO CHANGE?

### Shared decision-making

The Commission believes that shared decision-making on medication choices is essential to improving outcomes. Clinicians need to work with people to agree what medication works best for them and then be prepared to monitor the benefits and side effects over time. This means practitioners discussing medication options fully with service users, providing quality information so that informed decisions can be made, and hospital pharmacists providing second options where necessary.

**We recommend that all mental health providers should ensure that people with schizophrenia and psychosis (in hospital and the community) are aware of their right to request a review of their medication including, where appropriate, access to a specialist pharmacist, and are encouraged to exercise it in practice.**



**“If only one thing were to change I would want it to be the right for people to be consulted about the medicines prescribed to them – for them to make an informed contribution and for them to have the confidence and permission to come back and say: ‘I don’t like this one, what else can I try?’”**

David Taylor, Member of the Commission

### Prescribing practice

We are very concerned by what we have heard about continuing poor prescribing practice and feel strongly that further steps must be taken to eradicate this. Sadly, some psychiatrists seem to know little about the pharmacology and interactions of the drugs they prescribe. This lack of awareness has negative consequences for the person taking any medication prescribed to them.

**We recommend that the Royal College of Psychiatrists and the Department of Health should regularly repeat the National Audit of Schizophrenia on prescribing and make public its results so that not only Mental Health Trusts and providers but also service users and carers can see the performance of local services. Clinical Commissioning Groups should only commission mental health providers who are signed up to the audit and who provide plans for improving practice in response to any outlier results.**

The training of psychiatrists in personalised prescribing practice is crucial so that they can accurately match the needs of the person to the appropriate medication.

**We recommend that the Royal College of Psychiatrists works with other stakeholders to define higher standards for the training of prescribers. Prescribing modern antipsychotic drugs, especially in combination and in dosages that can be off-licence, is a specialist skill and as such should only be undertaken where the prescriber has the knowledge, experience and competence to do so.**

### Better drugs

Over twenty antipsychotics are currently available, including the newer atypical drugs, but all work because they block dopamine receptors in the brain. Whilst they are all effective to some extent none is completely effective in all people. Many service users are left with residual symptoms which lessen the quality of life and stop them fully participating in society. Clozapine is the most effective drug but the exact neuropharmacological reason for this remains a mystery.

Major concerns remain about the lack of efficacy and side effects of antipsychotic drugs. There is an urgent need for co-ordinated investment to secure improvements. The Commission is very concerned that little research is underway on better medications. This sits in strong contrast to other illnesses such as HIV AIDS where there have been dramatic developments in the effectiveness and side effect profile of medication.

**We recommend that the Department of Health works with representatives of the pharmaceutical and research communities to increase investment in research for new and improved medications for psychosis.**

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**What's been best for me:  
listening to and talking  
confidentially with people with  
varying other real life problems,  
some very serious; “clever”  
CBT from a good psychologist  
including writing down and  
analysing new paranoid ideas.**

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# ACTION TO IMPROVE ACCESS TO TALKING THERAPIES AND OTHER EFFECTIVE SUPPORT

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Our work suggests that despite the existence of NICE guidelines for schizophrenia, and user feedback on the importance of a range of treatments, access to interventions beyond medication remains limited. We view this position as totally unacceptable and argue that services should be commissioned in line with the evidenced-based treatment recommendations in the NICE guidelines for people with schizophrenia and their families, including access to evidence-based talking therapies.

## WHAT WE HEARD IN OUR EVIDENCE

In our survey, practitioners, people using services and their families highlighted the following interventions as the ones they most valued alongside medication.

- 43% CBT (Cognitive Behavioural Therapy).
- 34% Peer support.
- 22% Exercise prescriptions.
- 20% Family Therapy (though only 10% among service users).
- 17% Creative therapies (art and music).
- 14% Physical health checks.
- 13% Self-help strategies.
- 12% Complementary therapies.

We also asked about treatment problems. Feeling disempowered by the mental health system was commonly rated – by 57% of practitioners, 38% of family members and 40% of users of services.

**“My son does not appear to get CBT, or see the recommended psychologist (they are always on leave, not in job yet, or the waiting list just keeps growing), or go to courses with self-help strategies, or yoga, or meditation, he is only given drugs. The single challenge is to ACTUALLY PROVIDE meetings such as the above to give the people strategies to cope, and to meet others trying to cope. It is a very isolating illness.”** Family member

**“Receiving any CBT therapy and getting the therapy we deserve but cannot access – that’s what I want to see change.”** Service user

We were particularly concerned about the lack of access to CBT and other psychological therapies which are recommended in the NICE guidelines and can be very valuable in helping people deal with the impact of symptoms and in keeping them out of hospital.

There are similar issues relating to the availability of family therapy, even though it can generate cost savings for the NHS estimated at approximately £1,000 per service user over a period of three years.

While accepting that not everyone wants, or will benefit from, psychological therapies, we were shocked at the estimate we were given that only 10% of people with psychosis have been offered true CBT. A study in Manchester found that 22% people in the trial did not want CBT. However that still leaves a large number who did and are unlikely to be able to access any (Haddock, presentation to Commission – Manchester 2012). And it is not the one-off treatment course that is required but flexibility to ‘top up’ the course with extra sessions, to change therapist if the first one does not work out and to try guided online programmes as well.

It is often stated that acutely unwell people are unable to make use of psychological interventions, in particular CBT. However we heard that although it may be difficult to provide one-to-one CBT to an acutely psychotic person, psychologists need to be more willing to work within acute care teams and help support as well as supervise nursing staff, to provide a psychologically-informed approach to the work they do. This includes talking constructively and compassionately, listening and providing support and assertive encouragement to take up various treatments, including medication, ward activities and, crucially, exercise. As the person’s mental state improves, they should be better able to take up formal CBT.

We believe that the answer lies in enhancing the competencies of mental health professionals, and in particular psychiatric nurses, to deliver psychological interventions. In some areas as many as 50% of the staff had already received some training in the delivery of talking therapies, though we heard only 20% of staff were currently using those skills.

The barriers to making use of their skills in practice included:

- A lack of opportunity in the schedules of community mental health teams to deliver structured interventions.
- Relatively few clinical psychologists receiving adequate training in the treatment

of psychosis so that even where people were offered CBT, it was sometimes from psychologists lacking skills in the care of people with psychosis.

- Lack of capacity amongst clinical psychologists to provide the necessary supervision and training for psychiatric nurses, and to deal with the most complex cases.
- We were concerned at reports that clinical psychologist posts are being cut in some Trusts and at the consequences this would have for any ambition to expand access to talking therapies.

At our evidence giving sessions we heard great optimism about the potential of peer support to plug some of the gaps in the current treatment portfolio. This is professional peer support – paid staff members using their lived experience to support another’s recovery. We need to build upon the current evidence base which is limited by extent and quality to examine the value of peer specialists and look at cost effectiveness.

**“I felt that it was hard to accept that I was seriously ill and that I had to make major lifestyle changes including regular antipsychotic medication. I now understand the limitations of my illness but I work around these. I currently work as a peer support worker, working with those with mental health problems and hope to train as a psychiatric nurse.”** Service user

People should be supported in exploring other ways of managing their mental health, such as creative therapies, nutritional supplements, horticulture, gym activities and pet therapies. These do not have strong formal evidence bases, but some service users find them useful in building confidence, keeping busy and keeping well.

Finally our evidence suggests very clearly that people and families are frustrated by a “one size fits all” approach to treatment, which fails to account for their individual needs and preferences. We believe that there needs to be a fundamental shift in culture in services towards the model of shared decision-making so people get the treatment they want and which suits them.

## WHAT NEEDS TO CHANGE?

### Interventions commissioned in line with NICE guidelines

We believe that it is unacceptable that people do not routinely get access to treatments recommended in NICE guidance on schizophrenia and psychosis.

**We recommend that Clinical Commissioning Groups should ensure that they commission services for people with schizophrenia and psychosis in line with NICE and other good practice guidelines, including CBT for psychosis.**

### Right to an individual and personal care plan

We think it is crucial that shared decision-making is placed at the centre of the support and treatment process. Individuals under the Care Programme Approach have a right to a care plan and a named care co-ordinator but there are significant concerns about the quality of care plans. All care plans should give people an element of choice as to where they are treated and by whom and include goals which have been agreed by the person.

**We recommend that the Department of Health, as part of its current review of shared decision-making, commits to giving people using mental health services an element of choice as to where they are treated, with a particular focus on guaranteeing a right to a second clinical opinion and allowing people and families a bigger say in choosing a lead professional for their care.**

**“Time after time we heard the same thing. Fundamentally, what service users want is to be listened to, to have their experiences validated, to be seen as a person and not just a set of symptoms and to be given hope. Surely that’s not such a big ask?”**

Alison Brabban, Member of the Commission

### Improving Access to Psychological Therapies

There is an urgent need to expand access to talking therapies such as CBT and Family Interventions for people with severe mental illness. This needs to start with a different way of communicating with patients in acute wards and should be a priority for Mental Health Trusts. We welcome the establishment of a dedicated strand of work within the IAPT programme to address the needs of people with severe mental illness and the resulting establishment of national demonstration sites. We are concerned at reports that this programme may be discontinued with the transfer of responsibility to the NHS Commissioning Board.

We believe this should be achieved through enhancing the skills of the existing workforce, especially psychiatric nurses, with appropriate specialist support from psychologists for training, clinical supervision and the management of complex cases.

**We recommend that the existing nursing workforce, particularly in acute units, should be better trained to deliver simple talking and supportive therapies and that the Department of Health, in consultation with other stakeholders, should introduce a maximum waiting time for access to psychological therapies for people with severe mental illness which is embedded in the NHS Constitution. We recommend that the Department of Health and NHS Commissioning Board should agree arrangements for continuing the IAPT programme for people with severe mental illness beyond March 2013.**

### Peer workers

We believe there is a case for using peer workers in supporting people with schizophrenia and psychosis. Their experience of living with the condition and achieving a good quality of life, and of navigating their way through the mental health system, is extremely valuable as a supportive resource. However, it is essential that appropriate training and workplace support structures are provided for peer workers to be operating effectively and safely.

**We recommend that all mental health providers should review opportunities to develop specific roles for peer workers.**

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**We care for our 34-year-old son who lives in a flat. He is overweight due to medication side effects and a poor diet. He is self-medicating on drugs and alcohol and his physical health is getting worse. There is an attitude of “if it is not a problem to us, leave well alone”.**

**There is no attempt to look at alternative medications and support is minimal. His physical health is not checked. If we did not keep on chasing this and other issues up nothing would be done. This would not be tolerated if it was a physical ailment.**

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FAMILY MEMBER

# PHYSICAL HEALTH

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The fact that people with schizophrenia and psychosis die on average 15-20 years younger than the general population (Thornicroft, 2011, Chang et al 2011, Tiihonen et al 2009) was described to us as a “scandal”. The Commission believes that the neglect of people’s physical health cannot be allowed to continue.

## WHAT WE HEARD IN OUR EVIDENCE

We received a comprehensive review of policy and research literature on physical health issues as part of our evidence gathering process, with a call to “keep the body in mind”. We were told:

**“It is becoming increasingly clear that not only does the early phase of psychosis constitute a critical period for laying down future psycho-social disability but it is also a phase when the seeds of future physical ill health are laid down. These young people acquire cardiovascular risk aggressively in this early critical period, bringing with it new treatment opportunities for intervening early to prevent future cardiovascular disease, and to halt the further isolation of these young people from their peers through poor physical wellbeing.”** Professor Helen Lester and Dr David Shiers

There are four main reasons for the increased morbidity:

- Antipsychotic medications, mood stabilisers and some antidepressants all increase appetite and therefore can cause weight gain and obesity, and this can result in cardiovascular disease.
- Lifestyle factors play a part too. People with severe mental illness have poorer diets, take less exercise and smoke more than the

general population. They are less likely to practise safe sex and women, in particular, are more likely to be coerced and exploited.

- Poor access to healthcare and lack of clarity about who is in charge of the physical health of service users means that when people do develop physical disorders they are less likely to gain access to appropriate physical health interventions.

A startling finding is how quickly physical health deteriorates. For example, it is common to have weight gain of 5-6kg within two months of first taking an antipsychotic medication and this gets worse over 12 months (Foley & Morley, 2011).

## Physical health of people with schizophrenia and psychosis – some facts

- Prevalence of type 2 diabetes is 2-3 times higher for people with schizophrenia than in the general population.
- People with schizophrenia who develop cancer are three times more likely to die than those in the general population with cancer.
- People with severe mental illness are twice as likely to die from heart disease as the general population.
- 61% of people with schizophrenia smoke, compared with 33% of the general population.

**“Physical health problems are treated in isolation from mental health issues. An example of this is poor motivation. Most of the attention is given over to controlling psychosis and once this has been achieved medical staff seem to feel their job is over and pass the person onto social services and family. However, if the person is depressed and poorly motivated, they will not look after themselves properly and physical health problems then increase. A much more holistic approach is required.”** Family member

We repeatedly heard the concerns people had about the medication they had been prescribed and the negative effects this had on their physical health. All too frequently people put on weight but were not provided with any strategies to combat this and the physical health problems that resulted were often just left by the health professionals, either because they did not recognise their importance or because, as some individuals felt, they did not care.

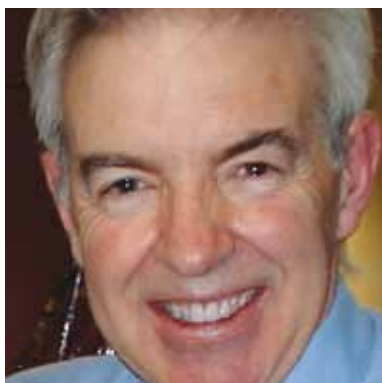
As a Commission, we are committed to improving outcomes for people with severe mental illness. Improving physical health is one area where significant gains can be made as long as there is recognition and awareness of the problem. We were struck by the fact that it is families and practitioners who rate physical health as a problem, far more than mental health service users themselves. It is worrying that service users are not empowered to make choices about their own health and wellbeing because they do not fully understand the risks they are running by continuing, for example, to smoke heavily.

We heard examples of good practice, but these were few against the weight of ignorance or denial that people have to cope with. We believe that this requires a more considered and holistic approach to caring for people with severe mental illness, from the acute ward to the GP. Getting to know the person well, in particular their family history, medical history, eating habits, activities and routine will all help to determine what kind of medication is least likely to impact negatively upon their physical health. In addition, promoting and prescribing exercise from the outset of treatment is vital.

While physical health checks are part of the payment system for GPs, these are failing to deliver an effective system of monitoring of the physical health of people with schizophrenia and psychosis.

Improving physical health is a civil rights issue. We have to address the problems with antipsychotic medication as well as the social determinants of poor physical health like poverty, social exclusion, poor diet, illicit drug use, a sedentary lifestyle and smoking. We welcome the inclusion of an indicator in the NHS Outcomes Framework to address this and, from our evidence, believe the following steps are crucial:

- Securing clarity of responsibility between primary and secondary care services for monitoring and managing the physical health of people with mental health problems.
- More training in physical health care and health promotion for all mental health practitioners.
- A programme of physical health monitoring and management integrated with the better prescribing and management of antipsychotic medication.
- Tailored health promotion programmes on exercise and healthy eating and helping people take more responsibility for their own health. These should start in acute care units. There is good evidence that exercise not only benefits physical health but also improves brain function.
- Finding a way to motivate people who access services to commit to healthier living as an essential individual priority and to maintain this in the longer term.
- Smoking cessation advice should be offered as standard and hospitals should be smoke-free environments.
- Better training for GPs. We welcome the Royal College of GPs’ emphasis on improving the skills of GPs in addressing the physical health needs of people with severe mental illness.



**“It’s so sad when one has cared for an 18-year-old at the time of their first psychotic illness and then one doesn’t recognise them when one meets them again 5 years later because they are 10 Kg heavier. Psychiatrists need to take more responsibility for the physical health of their patients because some GPs and hospital physicians don’t like treating people with psychosis.”**

Robin Murray, Chair of the Commission

## **WHAT NEEDS TO CHANGE?**

### **Focus on physical health**

It’s crucial we address the scandal of the poorer physical health experienced by people with severe mental illness. We welcome the inclusion of the early mortality of people with severe mental illness as an improvement area in the NHS Outcomes Framework. Now the indicators need to be developed, as a matter of urgency, for measuring progress in this area.

**We recommend that, as a matter of urgency, the Department of Health develops indicators for measuring reductions in the excess mortality levels among people with severe mental illness.**

We believe the workforce needs to be given the skills, confidence and motivation to address the physical health needs of people with severe mental illness. They must understand the importance of good physical health to recovery and wellbeing. Better cooperation between primary and secondary care services is needed to ensure that service users receive coordinated care and clinicians share clinical information to enhance people’s wellbeing.

**The Commission recommends that the Academy of Medical Royal Colleges, the Royal College of Nurses and the Health and Care Professions Council should place greater emphasis on physical health in severe mental illness in the training of all doctors, nurses and mental health practitioners. Mental health**

**practitioners, in particular nurses, should be able to demonstrate competence in providing basic physical health care and progression through training should be dependent upon this.**

We would like many areas of physical health addressed but one key action is to address the high levels of smoking among people with severe mental illness as an absolute priority.

**We recommend that each mental health provider works with the local Director of Public Health to ensure that there is targeted smoking cessation provision for smokers with schizophrenia and psychosis, with guidance from Public Health England.**

Crucial opportunities for managing the physical health of mental health service users exist when people are on acute care units. These opportunities are rarely taken. This is particularly important as physical health interventions should be introduced alongside administration of anti-psychotic medication and run concurrently together.

**We recommend that each mental health provider promotes the use of clinical tools to support the physical health needs of people with schizophrenia or psychosis on antipsychotic medication, and ensures that these are visible in every mental health ward in the country. These include the Lester UK Adaptation - Positive Cardiometabolic Health Resource.**

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**The hardest thing to do is to realise that your own thoughts and feelings and intuitions are not always correct, but it was also the single most important concept I learned in order to survive with schizophrenia. More emphasis should be made on educating those with the condition and how to cope with it. Guidance would be invaluable and would maybe assist their long-term recovery.**

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# SUPPORTING INDIVIDUAL RECOVERY AND QUALITY OF LIFE

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Support for people with schizophrenia and psychosis needs to be far broader than the clinical treatment options recommended in NICE guidelines. A range of other interventions are crucial to support recovery or maintain an acceptable quality of life like good housing, social support, employment or other meaningful activities that are central to achieving wellbeing.

We are very concerned about the impact which cuts in both the NHS and social care budgets are beginning to have in reducing what is available to support people with schizophrenia and psychosis in the community. This will have a devastating impact on the lives of individuals and will also lead to increased pressure on expensive hospital services as fewer people are able to manage successfully in the community.

## WHAT WE HEARD IN OUR EVIDENCE

People living with severe mental illness want the same things from life as everyone else – friends, housing and a job. In our survey people highlighted the following factors as important for recovery:

- 61% support from family.
- 57% stable housing.
- 48% self-management strategies.
- 32% support from friends.
- 28% help finding or keeping a job.

These are all crucial for maintaining wellbeing and recovery. Many of the key supports are not clinical treatments but friendship, stable shelter and meaningful activity such as employment. Services need to find ways of supporting

people's lives rather than trying to get people's lives to fit a service. To do this, service users and their families need to be at the heart of the decision-making process on how care is delivered and by whom. There is too little choice in the current mental health system.

Many services today are under immense pressure. Asked about the most difficult aspect of supporting people with schizophrenia and psychosis, practitioners cited the limitations of our current services and the inflexibility and fragmentation of the systems within which staff operate.

**“The system gets in the way – the piles and piles of paperwork, mandatory training, meetings etc that, whilst necessary to some degree, take me away from important client contact time and which gets in the way of good therapeutic relationships.”** Community mental health nurse

## Housing

We are concerned at the impact of cuts in support, particularly housing provision. This is likely to increase costs in hospital services, with estimates that homelessness can increase costs to the state by between £24,000 and £30,000 per year per homeless person (Department of Communities and Local Government, 2012).

Already, many people have to stay in hospital because of a lack of suitable alternative accommodation. The proportion of people in contact with secondary mental health services in England who live in their own home declined by 13.5% from 2011 to 2012. There has also been a 1.2% increase in people with mental health problems being permanently admitted to residential and nursing care (Local Government Association, 2012).

Local councils with social care responsibility need to look very closely at their strategies for ensuring that people are able to live independently in the community.

## Employment

Only 5-15% of people with schizophrenia are in employment, losing the English economy £3.4 billion per year. The condition affects young people of working age and causes a 64% decrease in the probability of being competitively employed as compared to the general population.

We believe more can and must be done to help people secure appropriate employment, including the use of individual placement and support (IPS) or job brokerage.

Only 25% of Mental Health NHS Trusts are currently investing in this approach. The NHS and social care bodies need urgently to address their own practice in relation to the employment of staff with severe mental illness. We received evidence from practitioners who have a mental illness that they felt they had to conceal because of the attitudes of their Trust. Recent data shows that, from 2011 to 2012, the employment of people in contact with secondary mental health services in England declined by 1.5% (Local Government Association, 2012).

**“Lack of understanding when trying to find employment – many of the ‘services’ provided for people are absolutely awful and not helpful and do not take into consideration that psychosis and schizophrenia affects people from various educational backgrounds: not just those with little education.”** Service user

We look forward to the publication of the Work Foundation’s study on Schizophrenia and Employment which we hope will present further evidence on how best to increase the proportion of people with severe mental illness in the workforce because paid work is good for mental health and improves clinical outcomes (Kilian et al, 2012). It is however important to emphasise that employment in many cases will require workplace adjustments and specialised support (such as what is provided through the IPS approach), at least initially.

## Benefits

Not everyone is able to work, or the required adjustments and support are not available locally. We need an approach which creates incentives for people to try paid employment but does not penalise them when they are genuinely unable to continue. We believe the current Work Capability Assessment is in need of radical reform. We have similar fears about the planned move from the Disability Living Allowance, on which many people with schizophrenia and psychosis depend, to the Personal Independence Payment.

Linked to employment, we heard about disrupted education and the problems of returning to college after periods of illness, which is extremely important both for employability and improving self confidence and self-esteem. It also impacts on the cost of schizophrenia and psychosis – for every person who does not gain a university degree there is a lost net benefit of £197,000 to society and for every incomplete BTEC qualification a 12% wage gain is forfeited which amounts to between £54,000 and £104,000 over a lifetime.

## Stigma and social recovery

**“Psychosis is very painful and very strange. People don’t understand you and find you difficult to be with. The most healing thing is others’ acceptance, love and kindness. I don’t think friends realised what it was like. Nobody called me when I was out of crisis to see that I was better.”** Service user

Stigma is a massive barrier to recovery and it can directly influence it. In our survey 1 in 2 people felt negative public attitudes towards people with mental illness affected recovery.

The Time to Change Viewpoint survey has found that overall levels of discrimination are falling but are still high: 91% of service users supported in secondary care in 2008 reported experiences of stigma and discrimination, falling to 87% in 2009 (Henderson et al, 2012). We have to continue with the progress being made in the Time to Change campaign to tackle stigma and discrimination if we want to see the genuine shift in public attitudes that people with mental illness desperately need.

A large part of the work of mental health services is to support people's social recovery. Mental illness can impact on relationships with family, friends, colleagues, neighbours – everyone. We heard that key barriers to recovery are feelings of isolation, mentioned by 44% of people with psychosis in our survey, and low confidence or self-esteem, mentioned by 46%.

Services must take interest in people's wider social support network when planning treatment and support programmes. We heard far too many cases where the social element has been lost in treatment and support planning. Occupational therapists, social workers, peer support workers and CPNs have a crucial role in not letting health concerns eclipse the social dimension of mental illness.

## Transitions

We were particularly concerned by the evidence we received from young people and their families about the persistent problems at the interface of care between youth mental health services (known as CAMHS) and adult services. The problems include poor planning, the difference in service ethos and approach, the family having to cope with changes in how they are viewed and valued, lack of continuity of care at a time when many feel very vulnerable and poor communication.

This is particularly difficult for looked-after children and young people in the youth justice system who have complex needs very often and are moving from several youth services to adult ones at the same time. These issues should be addressed by EIP services.

**“We need joined up working between CAMHS, adult and other mental health services, social services, housing, education and joint commissioning where possible to prevent bouncing people between services, falling between the gaps and duplication of work.”** Child psychiatrist

## Meeting the needs of the most disabled

We were especially concerned to hear about the experiences of people with chronic and enduring schizophrenia. Their clinical condition might be stable but their quality of life is, by any standards, unacceptable.

We believe that this is an area where personalisation has a key role to play. We heard stories about how personal budgets had transformed people's lives but they are not often used for severe mental illness, and not used at all in some areas of the country.

The latest data from 2011-12 shows that only 14% of people receiving social care services for a primary mental health need are receiving self-directed support (up 4.8% on the previous year), compared with a 43% average for all people receiving social care services, up 13.5% (Local Government Association, 2012). People with mental health problems are benefitting less than any other group from this key element of Government policy and worryingly are slipping further behind.

This must not be allowed to continue and every local authority and the NHS must support the implementation of personal budgets (or direct payments or self-directed support). This will mean more collaboration between health and social care, as currently a major barrier to delivering personal budgets is poor integration.

**“My son has done more in the past five years with his personal assistant than any time in his life since being diagnosed with schizophrenia. When I get a phone call saying ‘I am in London, I’m about to go to the theatre...’ for me to know he is happy, that his quality of life has improved, is wonderful.”** Family member

We also recognise however that personal budgets may not work for everyone with schizophrenia or psychosis and that this must not be an excuse for services failing to provide an adequate level of support to meet the social as well as clinical needs of individuals.

## WHAT NEEDS TO CHANGE?

**“From the outset I was very interested in the recovery prospects of people with schizophrenia and learning more about how to improve things for those with this condition. As a Commissioner, I think we have found a lot of the answers but we rely on the powers that be to action the changes needed to deliver on them.”** Terry Bowyer, Member of the Commission

### Recovery-focused services

We believe that the principles of recovery-based practice should be at the heart of providing services for people with psychosis including those with a diagnosis of schizophrenia. Mental health services need to work in a way that places the interests, perspectives, strengths and aspirations of the person being supported at the centre. Fundamentally, it requires active listening and treating the person with respect, as someone who can take an active role in their own life. There needs to be a significant shift in practice and new ways of working need to be reinforced through training and development.

We were impressed by what we heard about the ImRoc (Implementing Recovery through Organisational Change)<sup>3</sup> programme delivered by the NHS Confederation and Centre for Mental Health as a vehicle for transforming the approach of mental health services by addressing training needs and simultaneously changing the way in which services operate. It involves a shift in the practice and culture of mental health services from treatment and ‘doing to’ to an empowering, learning opportunity for people to recover and learn how best to live their lives with or without persistent mental health problems. In ‘Recovery Colleges’ treatment and therapy for patients becomes courses and training for students.

**We recommend that all NHS Mental Health Trusts and other mental health providers should invest in recovery-focused whole system transformation and development for staff such as ImRoc.**

### Employment

We believe more could be done to help people with psychosis secure or sustain employment. There is a strong case for the adoption of employment support using the model of Individual Placement and Support (IPS). Research has shown that where IPS is adopted fully it can bring about employment rates of up to 60%.

**We recommend that all NHS Mental Health Trusts and other providers adopt the Individual Placement and Support (IPS) model and ensure that employment support is effectively integrated with clinical services. We believe such support may be best provided by voluntary sector organisations being co-located with clinical teams. Outcomes will also be improved where Mental Health Trusts work closely with Work Programme providers.**

### Personal Budgets

We are impressed by the evidence on how personal budgets can be used to help people secure the support they need and increase control over their own lives. This is supported by pilot work which suggested that people with mental illness could benefit from personal budgets (Glendinning et al 2008). Yet worryingly few people have been given this option with only a handful of places offering it for people with schizophrenia or psychosis. We believe there is a strong argument for promoting them further and welcome the right to a personal budget which is included in the Social Care Bill.

**We recommend that all local authorities, NHS Trusts and Clinical Commissioning Groups should integrate and actively promote personal budgets, where appropriate, for people with schizophrenia and psychosis and ensure that adequate support is available for those who choose to manage a direct payment. Local Councils should report specifically on their progress in introducing self-directed support for people with mental health problems and should set themselves stretching targets to improve their performance. Far more integration between personal health and social care budgeting is required to deliver value for money.**

3. Information on ImRoc: [http://www.centreformentalhealth.org.uk/recovery/supporting\\_recovery.aspx](http://www.centreformentalhealth.org.uk/recovery/supporting_recovery.aspx)

## Housing

Good housing is central to recovery and good outcomes. We are concerned at the evidence about the negative impact which difficulties in securing appropriate and affordable housing and housing related support have on the health of people with schizophrenia and psychosis. We are also concerned that this delays discharge from acute and secure care.

**We recommend that Health and Wellbeing Boards ensure the housing needs of people with severe mental illness are adequately addressed.**

## Welfare reform

We believe the current Work Capability Assessment is not fit for purpose for people affected by mental illness and is in need of reform. The design of the assessment does not accurately identify the barriers they face in a working environment.

There is also a low level of mental health expertise amongst assessors. Schizophrenia and psychosis can make it more difficult to complete the application and assessment process. Sadly, therefore, some of the most vulnerable claimants are potentially being excluded from the support they are entitled to.

This is particularly concerning given the current onus on applicants to supply their own medical evidence to support their application. Medical evidence can be particularly beneficial in cases where claimants may have problems reporting their own capability, for example through lack of insight into their condition. The value of this evidence to the assessment process is well documented and can result in fewer unnecessary and distressing face-to-

face assessments. We believe that in cases where people are too unwell to coordinate the collection of this medical evidence, there should be an onus on the organisation carrying out assessments to do this.

**We recommend that the Work Capability Assessment process is amended for people with schizophrenia and psychosis to require the Department for Work and Pensions to seek information from health professionals to guide decisions rather than requiring potentially vulnerable people to navigate complex systems in order to provide it. The same principle should be built into plans relating to any qualifying assessment for the new Personal Independence Payment.**

## Looking after the most disabled

Across the country access to social care by people with schizophrenia and psychosis is inconsistent. To overcome this, the Government is currently setting a national eligibility threshold through the Care and Support Bill regulations. We are concerned that the social care eligibility threshold will be increased so that people with schizophrenia who are deemed to have 'moderate' needs (often due to their condition fluctuating) will lose support. Without this, a person's mental health condition may deteriorate, resulting in a crisis and requiring access to more costly health or social care interventions, and possibly use of compulsory powers of the Mental Health Act.

**We recommend that when the Government sets the national social care eligibility criteria, guidance ensures that people with fluctuating conditions who need on-going support to remain independent do not lose services.**



**“I have been shocked by recent figures which show how much people with mental health problems are missing out on self-directed support. This is compounded by the lack of awareness of the usefulness of direct payments and is an indication of the need to change the culture in mental health services so that people are more in control of their lives.”**

Jonathan Phillips, Member of the Commission

## Harminster's experience

"I am a 40-year-old South Asian woman who has had schizophrenia for seven years. Here are my thoughts on its treatment today.

My local crisis resolution team is always in crisis. The service is very stretched and the staff are burned out. People are at their most vulnerable when they are relapsing and a well resourced service that can intervene quickly is needed. There seems to be a move towards recommending home treatment over a hospital stay for service users who are relapsing in order to save money.

Home treatment simply doesn't provide the level of support needed when relapsing and it puts an unbearable burden on carers. Services seem to be under increasing pressure to reduce the length of hospital stays. Again this puts pressure on carers and is more likely to lead to repeated admissions.

More attention should be given to sexual safety on the wards, particularly on mixed wards. More intensive home support is also needed for the period immediately after discharge from hospital.

Receiving a diagnosis of schizophrenia is very traumatic and most people do not know someone who lives openly with schizophrenia and who is living a happy and rewarding life. Peer support workers go some way towards addressing this and they should be available across the UK.

There should be an English Recovery Network (like the Scottish Recovery Network). A new name for schizophrenia should be considered too as it carries a lot of stigma and many people do not know what it means."

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**For services to work effectively, staff need regular supervision from senior clinicians and managers who have a responsibility to remove the blocks to effective working.**

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NEIL CARR  
MEMBER OF THE COMMISSION

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**Growing up with a parent with schizophrenia was not easy. It was something we told no one about. My own descent into mental health was not recognised by my Asian church community who blamed me heavily, very nearly destroying me in the process.**

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# MENTAL HEALTH AND MINORITY ETHNIC GROUPS

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There are many ethnic groups living in the UK and their experience of mental health services varies. The Commission heard a number of concerns:

- Too much treatment involves coercion under the Mental Health Act, over emphasis on medication and not enough talking treatments.
- Lack of understanding of specific cultural issues affecting a population.
- The stigma and shame of seeking help hinders the delivery of any kind of support.
- Denying ethnic differences and ignoring the very real problems affecting people from BME communities.

Some progress has been made: staffing, for example, is now more representative of the population being supported in many areas and the national BME mental health network has expanded. However, many service users from minority backgrounds feel mental health services are based upon a western understanding of mental illness which they do not share and there are very particular concerns over the diagnosis of schizophrenia.

## WHAT WE HEARD IN OUR EVIDENCE

### Minority ethnic communities

Research is helping us to understand some of the variations in service use and experience. The EMPIRIC and AESOP research studies looked at the population rates of mental health symptoms in different ethnic groups. As with other studies (King et al, 2005; Fearon et al, 2006), both found that people of African-Caribbean and African origin have the highest rates of psychosis. These high rates are not found in the Caribbean, indicating that it is not being black that increases the rates but being black in Britain.

Socio-economic factors are drivers of these findings with those from poorer backgrounds, those living in inner cities and those encountering adversity and discrimination being at particular risk. Cultural differences in the expression of mental distress and in readiness to accept help may be important in some BME communities.

This indicates that a more sophisticated understanding and approach to an individual's personal cultural background is required. Mental health practitioners need to have the cultural competence, awareness and flexibility of thinking to recognise the different health responses that exist within different cultural groups. Treating everyone as though they are the same is wrong; diversity needs to be acknowledged and respected.

Themes which repeatedly emerged during evidence to the Commission were the questioning of the reliability and validity of the diagnosis of schizophrenia and models of intervention which are focused on medication. This theme was particularly pronounced in discussions about the experience of black and minority ethnic groups. It was argued that the flaws in the mental health system (namely problems with categorical diagnosis and the undue influence of drug companies on professional education) have disproportionately negative impacts on black people.

The commission was presented with evidence that suggested that the levels of distress and behaviours that lead to a diagnosis of schizophrenia need to be understood in a broader social context. We accept this and believe that greater efforts are required to understand people's experiences and why it is that different social contexts lead to different levels and expressions of distress – for example raised rates of diagnosed mental health problems in England compared with in the Caribbean.

The Commission considers that tackling social inequalities and disadvantage will help to reduce the level of psychosis seen in all BME groups. And because migration is associated with the development of psychosis, mental health and social services should gear up to work with newer immigrants into the country, especially refugees from war and torture. Those from the Middle East, Afghanistan, Central and Eastern Africa are likely to be at greater risk of psychosis because of the trauma they may have experienced and ongoing social adversity.

The Commission notes that BME service users have less access to talking therapies (such as IAPT) for common mental disorders and CBT for psychosis. Although there have been improvements in the diversity of certain parts of the mental health workforce, especially nurses, doctors and occupational therapists, this cultural diversity is not reflected in psychology, even in inner city areas. The Commission feels that this may impact on BME people accessing psychological therapies and a long-term strategy should be put in place to improve the ethnic diversity of the clinical psychology profession.

The Commission also feels that schools should give greater emphasis to mental health promotion as part of their PHSE timetable. In inner city environments where the risk of severe mental illness is greatest, the emphasis on early detection should be paramount.

Mental health means different things to different people and communities. Mental health services must adopt a holistic and sensitive approach with all their clients but it is of particular importance with BME communities. Working with specialist voluntary sector organisations such as the Chinese Mental Health Association, Afiya Trust, Black Mental Health UK and Diverse Minds can assist greatly.

We are concerned that services tailored to the needs of minority groups will be victims of the pressure to restructure services. We heard that a number of voluntary organisations providing support to BME people with lived experience had been or are likely to become victims of the local authority cuts. For some people these may be the only link with mental health support, particularly as they may have negative experiences of mainstream psychiatric

care. Given the poor outcome of BME people in mental health services, there need to be third sector alternatives which can support people and direct them to mainstream services.

## Black Communities

**“I have a personal friend who is a six foot tall male who experiences episodes of psychosis. He is always stigmatised as being dangerous because he is big and black with a mental illness.”** Carer and mental health advocate

It continues to be the case that people from African-Caribbean and African backgrounds experience greater dissatisfaction with mental health services than their white counterparts.

People from African-Caribbean and African backgrounds are more likely to be given a diagnosis of schizophrenia or psychosis. They are more likely to be admitted to hospital under section and for there to be police involvement in their admission. They are heavily represented in locked and secure forensic units. They are more likely to be detained under forensic sections. Black people are less likely to receive psychological therapy and more likely to complain of being restrained and forcibly medicated. It is not surprising that dissatisfaction with mental health services is high amongst the population with significant distrust of services.

Over the years, mental health services have worked to improve outcomes for black service users, but there continues to be a high level of dissatisfaction, with many in the black community concerned that racism is at the heart of the inequality seen in service provision. The Commission considered this at length. There needs to be ongoing vigilance around the risk of unconscious cultural stereotypes being used to make decisions about diagnosis, treatment and placement.

The black population in the UK is highly diverse and there are significant cultural differences with respect to mental illness. Emotional and psychological distress is often not seen as something that can be helped by the medical profession. The families of black service users often do not report concerns for some time and paradoxically, sometimes when they do, they call the police before a doctor (Morgan et al, 2008).

While sadly there will be people with racist attitudes in the mental health system as in all areas of society, we do not think that there is systematic racism. By and large mental health professionals are sympathetic to the problems of BME groups but so far have not found the way to improve outcomes and satisfaction with the services. This is an area where much further effort is needed.

Black people are over-represented in locked and secure psychiatric units. This means they will be more likely to be exposed to forced medication and restraint. We welcome the fact that psychiatric services have responded to the findings of the Rocky Bennett inquiry and have taken more proactive approaches to managing acutely disturbed people in acute care units. All psychiatric units should be using Promotion of Safe and Therapeutic Services (PSTS) approaches, which emphasise verbal de-escalation and techniques to manage acutely disturbed behaviour in as safe and compassionate a way as possible.

Black people in the UK are more exposed to some of the factors associated with increased risk of psychosis such as living in the inner city, poor education, unemployment and discrimination (Morgan et al, 2008). The focus should be on intervening early in their lives, in particular focussing on keeping families together, providing extra employment opportunities and support in schools. Mental health promotion campaigns targeted at BME populations are imperative.



**“The evidence about social adversity and mental illness was striking. I look after people with severe mental health problems. I am frequently struck by how much they have in common. So many have experienced horrendous emotional trauma and significant social deprivation regardless of whether they were born in the Caribbean, Afghanistan, Surrey or around the corner in Lambeth. All too frequently I wish that someone had intervened when the person was 4 or 5-years-old. All those factors which combined to bring them to my service may have been avoided. Is psychiatry the problem for most of my patients? Not where I work. It is imperative that we work at tackling the social inequalities that cause poor mental health. Doing so will undoubtedly improve the outcome for everyone, including those from BME groups.”**

Shubulade Smith, Member of the Commission

## WHAT NEEDS TO CHANGE?

A preventative approach is required to address the mental wellbeing needs of minority ethnic communities. Not enough attention is paid to tackling the factors which occur early in life and which cause mental illness later on. This could, we believe, make a big difference to many lives.

**We recommend that clinical commissioning groups and providers work together to deliver a range of preventative, secondary and acute care services underpinned by cultural competency principles to meet the needs of diverse local populations.**

We are concerned that health and social care planning, as well as broader community development strategies and programmes, ignore the needs of specific BME communities because they do not get to hear about their needs and concerns. There are many reasons for gaps in understanding but it is vital they are addressed.

**We recommend that Health and Wellbeing Boards ensure there is a strategy in place which specifically addresses the needs of minority ethnic groups in their communities. The strategy must include an emphasis on mental health promotion as well as providing personalised care which must be culturally competent.**

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**We discharge too many people with complex problems into a community that hasn't got the resources to help them.**

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# MEETING THE NEEDS OF THE MOST MARGINALISED

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Within the wider population of people affected by schizophrenia and psychosis we were concerned about the experience of a number of groups who are already marginalised:

- People with schizophrenia and psychosis in the criminal justice system.
- Homeless people.
- People with a “dual diagnosis” of addiction problems and severe mental illness.

The Commission acknowledges that the issues relating to marginalised groups would warrant separate inquiries of their own but there are a number of major issues we want to highlight.

## People in the criminal justice system

**“I have had a severe mental illness that led me to commit a crime against a member of my family many years ago. I have had generally good care but sometimes there are occasions when staff within secure units seem almost sadistic to those within their charge. I think this stems from boredom. I am now living in the community. I usually work and I find it hard to make ends meet like everyone else but I am always ‘looking over my shoulder’ in case neighbours or acquaintances know my past.”** Service user

There are far too many people with psychosis in the criminal justice system. At least 8% of prisoners suffer from a psychotic illness, with estimates that 2% have schizophrenia compared to a population average of 0.5% (Singleton et al, 1998). Similarly, there are a large number of people in secure hospitals who could be managed better in less restrictive environments without risk to the public. 1 in 4 people in secure hospitals are detained for over 10 years (Rutherford and Duggan, 2007). The human cost, even before the financial cost, is immense.

Factors which contribute to this include substance misuse, chaotic lifestyles, childhood abuse and trauma, family breakdown, poverty, stress and homelessness as well as failures to intervene early or effectively. Our two members of the Commission with lived experience of schizophrenia have both been in prison.

There is a 54% re-offending rate among those with mental health problems, creating a revolving door between prison and the community. But most people with severe mental health problems are in prison on short sentences. There is a strong cost effectiveness case for the use of suspended sentences or community orders and an appropriate package of community based mental health support. However, prisoners told us that they prefer to be inside than out because of the lack of support on release. Services are not geared up to meet their complex needs.

Many people with psychosis who end up in the criminal justice system have been previously known to services and, in some cases, the failure of mainstream services to engage or keep in touch with individuals in need is the precursor to offending behaviour. Failure to treat emerging problems means we are failing individuals and wider society. Early intervention for conduct disorder saves £7.89 for every £1 worth of investment whilst prevention programmes such as parenting programmes and Family Nurse Partnerships save £83.73.

The Commission visited one prison with an excellent prison healthcare service. We were told by experts in the field that this was as good as it gets, but even here it was hard to comprehend how someone managing a psychotic illness could cope.

We welcome the Government’s announcement that it intends to fund the development of a national network of diversion and liaison teams which can work with the police and courts to support people with mental health problems

who come into contact with the criminal justice system. These teams could play a particularly important role in working with people with schizophrenia and other psychosis, helping those who are already known to services and ensuring that they are supported by mainstream services.

We are interested in the work done by the Centre for Mental Health on the poor use of Mental Health Treatment Requirements. Of all community requirements applied, only 0.3% are for people with mental health problems, despite estimates that 43% of people with a community sentence have some sort of mental health problem (Soloman and Silvestri, 2008).

We believe there should be much greater use of community sentences (with treatment requirements relating to mental health or substance abuse as appropriate) rather than custodial sentences for people with psychosis where neither their offence or the risk they present to others warrants it. While we accept that community sentences should not be seen as a “soft option”, the insistence from the Ministry of Justice that all community sentences should have a punitive element will be counterproductive for this group.

In the short term it is crucial that quality care is available. We want to see families’ experiences of the criminal justice system vastly improved and a recovery ethos embedded in approaches to prison mental health and secure care. The system must become more hopeful and less risk adverse without shying away from its duty to protect the individual and society.

We recommend that the Department of Health and Ministry of Justice ensure that the commitment to establish diversion and liaison teams in every area by 2014 is followed through. Such teams, working with mental health services, the police and sentencers, should focus on helping to reduce the number of custodial sentences for people with psychosis where neither their offence or the risk they present to others warrants it.

## Homeless People

**“My son has suffered from mental illness since the age of 16. He is now 32. He was not given a diagnosis of schizophrenia for the first 10 years. He was sometimes chaotic, violent towards me, homeless and desperate for help. I was very strongly advised by his psychiatrist to cut my ties with him and make him homeless. I did not take his advice but it eventually happened because I could not cope. I am convinced some of his paranoid ideas are rooted in his homelessness experiences. Being homeless did not help in any way.”** Family member

Many offenders have been homeless and have addiction problems. It is estimated that 30% of people who are street homeless have a mental health problem and the homeless are 50-100 times more likely to have a psychotic disorder than the general population. Street homelessness is on the increase too: in London during 2011/2012, 5,678 people slept rough, up 43% on the previous year. A study in London and Leicester found 33% of service users had been homeless at some stage and 13% roofless (Bebbington et al, 2005).

High risk groups for schizophrenia and psychosis among the homeless include women, refugees and asylum-seekers, people from BME communities and care-leavers. There are significant health concerns in terms of physical health and emotional wellbeing. This group also finds it difficult to look after themselves and few are registered with a GP.

We heard about the difficulties of engaging homeless people with traditional services and of the importance of services being proactive. Assertive community outreach teams seem to make a difference. These have an extensive network of partners providing expertise on housing, probation, benefits etc. alongside therapy and medication. This ‘one stop shop’ model can bring hope to those who feel society has discarded them. In the US, ‘critical time’ interventions which manage transition from acute care settings to the community for those at risk of homelessness have been successful. Unfortunately, there is little evidence for what works best so we need to evaluate long-term impacts and disseminate good practice.

**We recommend that Clinical Commissioning Groups and local authorities should ensure that the needs of people with schizophrenia and psychosis who are homeless are captured in their Joint Strategic Needs Assessment and reflected in local commissioning plans.**

## Drug use and psychosis

**“Putting sectioned drug users/alcoholics back out onto the streets with little or no support is nothing short of criminal.”** Family member

People with psychosis take more drugs than the general population, especially stimulants and cannabis. A recent European study found substance dependence in 42% of the London population with psychosis, ranking it 1st out of eight cities (Carra et al, 2012). They don't however take more alcohol or opiates.

It has been known for many years that the heavy use of stimulants such as amphetamines and methamphetamine can lead to psychosis and in recent years it has become clear that substances with similar pharmacology such as Khat and “legal highs” can do the same. Most recently concern has focused on cannabis since this is the most widely used illicit drug, and people with psychosis take it more frequently and for longer than the general population.

The critical question is whether the heavy use of cannabis has contributed to the onset and persistence of the psychosis. Here, the evidence has been mounting steadily over the past 10 years and all competent studies have shown that initially healthy people who use cannabis daily are more likely to go on to develop psychosis in the ensuing decades than people who don't (Casadio et al, 2011). Those with a family history of mental illness, those with a suspicious or psychosis-prone personality, and those who start use in early adolescence, also appear to be at greater risk.

Those people with psychosis who continue to smoke have a worse outcome too, with more persistent symptoms, repeated hospital admissions, and they show more aggression. Drug use not only results in more people with acute psychosis but many of those who are too dependent on cannabis to stop are repeatedly readmitted to acute care units as they relapse.

Sadly, few Trusts have dedicated dual diagnosis teams that are sufficiently skilled to take on these service users and successfully get them to decrease or stop their cannabis consumption. But dual diagnosis is extremely costly to society, even before the human costs are considered.

In south London over a decade ago researchers found over a six month period the cost per service user was £1,469 more for those with schizophrenia and substance misuse (McCrone et al 2000). Many of this group are known to the criminal justice system as well. Individuals with schizophrenia and substance use co-morbidity had 4.4 times the risk of committing violent crime compared with the general population. The risk among those without co-morbidity was only 1.2 times higher (Fazel et al, 2009a).

The ingredient in cannabis which provokes psychosis is tetrahydrocannabinol (THC). Experimental studies show that when THC is given intravenously psychotic symptoms can be produced, especially paranoid delusions.

However, there is another substance in traditional cannabis called cannabidiol (CBD) which appears to decrease anxiety and counteract the psychotogenic effects of THC. For example, traditional hash (resin) contains about 4-5% of each of these while marijuana (weed) a bit more THC and less CBD.

But in recent years plants have been bred which produce much higher THC levels and the resulting type, sinsemilla or “skunk”, has taken over much of the market in countries such as England and Holland. Unfortunately, as the THC goes up so the CBD goes down so that the skunk used in England has a THC concentration of up to 18% and practically no CBD.

Recent evidence suggests that skunk is more likely to provoke psychosis, not just because of the higher THC levels but also because of the lack of the balancing CBD (Di Forti et al, 2009).

Another worrying trend is the age that people start smoking the drug. It is getting younger with over a third of 16 year olds in England now having tried it.

There has been considerable dispute over the legal classification of cannabis but evidence suggests that this is not crucial. What is more important is education about the risks, and it seems that the greater knowledge about the risks of cannabis has had an effect on the amount smoked. So over the last decade cannabis consumption has declined in England and in many other Northern European countries (in the case of England by about 15%).

Two initiatives are urgently required. Firstly the development of expertise in the mental health system for treating people with psychosis and drug problems. Secondly a high profile educational campaign pointing out the risk of heavy cannabis use, particularly of high potency forms.

We recommend that Public Health England and the NHS Commissioning Board work together to ensure that mental health and substance misuse services are commissioned to provide people with co-occurring severe mental illness and drug or alcohol misuse with integrated care and treatment to support their recovery.

**We also recommend Public Health England lead a high profile educational campaign pointing out the risk of heavy cannabis use at an early age, particularly of high potency forms.**

## Violence

A well-established myth is that having a psychotic illness such as schizophrenia means that someone is highly likely to behave violently. These stereotypes have been reinforced by the media.

In reality serious violence amongst people with schizophrenia and psychosis is rare and the annual risk of someone with schizophrenia committing a homicide is 1 in 10,000 or 1 in 150 for being convicted of a violent offence. Put in context, it has been found that people with schizophrenia and psychosis are responsible for about 5% of violent crime in society (Fazel and Grann, 2006).

Researchers have, however, been divided as to whether or not schizophrenia and psychoses are associated with violence, with some studies showing an association whilst others show little relationship (Steadman et al, 1998; Wallace et al, 2004). Seena Fazel and colleagues in Oxford have produced one of the most authoritative articles in this area. Their metanalysis of 20 papers found that, while there was an increased risk of violence relating to schizophrenia and psychosis (this was particularly so for women), this increased risk of violence was mainly mediated by substance misuse (Fazel et al, 2009b). The researchers found that the risk of violence in people who misused substances but had no psychosis was similar to that seen in people who misused substances and had psychosis and this was higher than the risk of violence in people who just had psychosis alone.

Their findings suggested that people who misuse substances are more dangerous than people with schizophrenia or psychosis. When substance misuse was taken into account, the increased risk of violence in schizophrenia and psychosis was small compared with the risk in the general population (1.2 times compared with over 4 times the risk in those with psychosis who misuse substances). Fazel et al (2009c) postulated that the small increased risk of violence not related to substance misuse is likely to be related to other familial and early environmental (criminogenic) factors rather than anything to do with the illness itself. However, illness factors may still be important in determining the type of violence that is seen if it occurs (Swanson et al, 2006).

The expert evidence presented confirmed the importance of early conduct disorder and antisocial behaviour on the risk of violence in psychosis and schizophrenia. Those who have developed in an environment where violence is used as a coping mechanism are more likely to behave violently if they become psychotic, but this is no different to their non-psychotic siblings who are more likely to use violence.

We concluded that the reports of excessive violence associated with schizophrenia and psychosis are misleading. The focus should be on the risk associated with substance misuse and familial and environmental risk factors for violence. To reduce violence risk it is imperative that mental health services are able to provide





**“It is an indictment of our society that so many people with schizophrenia and psychosis end up in prison or are homeless. People with a severe mental illness deserve something better.”**

Paul Jenkins, Member of the Commission

early preventative and ongoing work around substance misuse for all clients, in addition to treatment of their mental health problem. Clinical commissioning groups and Health and Wellbeing Boards should prioritise Dual Diagnosis and expect Mental Health Providers to have a coherent strategy in place to minimise substance misuse in their client group. This will go some significant way to reducing the violence risk and ultimately the stigma associated with schizophrenia and psychosis.

The media also have an important role to play. We urge journalists to understand that, contrary to public perception, people with schizophrenia and psychosis who commit violent crime often do so for the same reasons that anyone else might. Journalists should report on these factors rather than simply report the person’s mental health problem.

**We recommend that the Press Complaints Commission or its successor body should work with mental health organisations to define standards in the reporting of violent crime involving people with a mental illness.**

## WHAT NEEDS TO CHANGE?

The wider recommendations we are making across our report are crucial to help better meet the needs of marginalised groups. However, there are a number of additional recommendations aimed at reducing inequalities within the overall population of people affected by schizophrenia and psychosis.

The clear implication of our report is that psychosis can affect every aspect of someone’s life as well as the people around them. A narrow clinical response is woefully inadequate and Health and Wellbeing Boards will have a key role as the guardians of this broader agenda.

- It is crucial that the needs of people with schizophrenia and psychosis are captured in Joint Strategic Needs Assessments.
- Early intervention can make a big difference to outcomes.
- Good inter-agency working is crucial in working with people with complex needs and this needs to be reinforced.
- There are challenges for the workforce in responding to the needs of people from different communities and with specific needs which must be addressed.
- Funding should be redistributed towards community based and prevention activity.

“

**This is one example among many we heard of a carer who had to battle for adequate services over long years. Many give up or crack under the strain.**

**Surely a civilised society should recognise, support and applaud what they do!**

”



LIZ MEEK  
MEMBER OF THE COMMISSION

## **A family experience by Ros**

“My son developed paranoid delusions 14 years ago. It has felt like an emotional roller-coaster. We have had 14 different psychiatrists and 24 changes of psychiatrist. We have had about 15 changes of key worker or care co-ordinator. So it’s hardly surprising that my son “does not engage with services”.

We were told the prognosis was poor and that he would probably always need secure rehab. But now with a lot of support he is managing to live in his own house and for the past six months he has been working in a garden one or two mornings a week. He is slowly regaining some self-esteem and confidence, but it’s been a rocky road to get here and we have had to overcome some major obstacles, not least the battles we’ve had with service providers.

I have a lot of conflicting feelings about medication. I can see that for some people it has made a dramatic difference, but not for my son. The trial and error process has been very difficult, especially when some medications appeared to make him worse. The physical side effects have been frightening too. I worry that his present condition might have been caused by some of the earlier medications he was prescribed and some of the awful things that happened to him in hospital.

Ideally what I would like from services is the best possible service for my son and, as a minimum, caring committed staff who spend time with him and really get to know him, who respond to his needs and who can advise us on how to manage the challenges.

I want him to have a fulfilling life and to be valued for who he is. I’d like hospital staff to have more supervision and training in how to diffuse aggression and I don’t think it’s acceptable that there are still some staff who humiliate and patronise the vulnerable people in their care.

I’d also like to be truly involved. I would like to be kept informed of changes in the service, and changes of staff and consultants. I’d like my carer’s assessment to be more than a tokenistic paper exercise. On a personal level I would like an acknowledgement of my input and my experience; to be listened to and for my concerns to be taken seriously.”

“

**He was 20 years old when he died. What I found hard as a carer was having to fight for everything to get what he needed – it’s stressful enough to discover your child has schizophrenia.**

”

FAMILY MEMBER

# FAMILIES AS PARTNERS NOT PROBLEMS

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We heard from over 1,000 families. Caring for someone with psychosis, especially schizophrenia, can take a tremendous toll, especially for those caring over decades for a person with a severe and enduring mental illness.

We use ‘families’ here to refer to friends and significant others as well as blood relations. Sadly, not everyone with schizophrenia or psychosis has a supportive family network, or one that is helpful to their recovery, but those that do need far more from services, and their families need be treated with respect, to be valued and heard.

## WHAT WE HEARD IN OUR EVIDENCE

**“I have never been given a diagnosis and effective treatment plan for my son over two and a half years. As prime carer we need to be fully involved and have access to a clear understanding of the condition and how we can help.”** Family member

It is frightening dealing with severe mental illness. Most families are ill-prepared to cope, knowing little about what to expect except unhelpful and stigmatising stereotypes. Families vary greatly in how they view the problems they face and their level of involvement but one common experience is frustration with the current mental health system.

Service users also vary in how far they want their families involved. In some cases families or a traumatic childhood contributed to the condition. A critical and very difficult challenge for the mental health system is balancing the needs and wishes of families with those

of service users, particularly during acute paranoid episodes. Families are not always part of the solution and can sometimes be at the root of the problems. However it is unfortunate that the legitimate concerns about the role of some families has meant that the large number of caring and supportive families are treated very poorly.

We estimate some 50% of people with severe mental illness have active family involvement in their care. More families would probably be involved if the system were more sensitive to their needs, and if society was less stigmatising and families better supported to cope.

Grief, exhaustion, anger and fear for the future were the most frequent emotions expressed to the Commission by families, along with tangible evidence of enduring love through great adversity for the person they look after.

The impact on carers’ own health and wellbeing must not be forgotten either. We know carers providing substantial and regular support are at risk of developing mental health problems themselves. The whole family is affected –

children caring for parents, brothers and sisters, parents and partners, the extended family and friends. But these vital support networks can also be the key to recovery. The mental health system must do far more to support families and work alongside them. After all, carers for people with schizophrenia and psychosis save the public purse £1.24 billion per year.

We heard from one sibling carer about the dilemmas her family face supporting their brother with schizophrenia who is 35 living in a residential nursing home. Caught between caring for him and trying to balance the demands of her own life, she worries about his care and treatment and is frightened to speak out in case his care is impacted negatively. "My brother is being left to rot. Nobody is doing anything to make him better."

**It's even harder if your loved one ends up in prison or in the secure care system where the approach to carers is more alienating and hostile. As one carer explained: "I naively believed that a High Security Hospital would be the source of experts in treating the illness ... instead I found a flagrant disregard for any external guidance and confusion as to whether a person should be treated for their illness or punished for their crime. And as a carer I was simply abandoned at the door."**  
Family member

Families and the person they care for need much greater choice and influence over the management of severe mental illness. This does not mean infringing on principles of patient confidentiality or that risk assessments have to be abandoned, but they should be applied with common sense and regularly reviewed.

The Commission heard harrowing accounts of the burden experienced by carers for long periods. They heard about the sorrow and sense of loss of the child, brother or sister they once knew and the perpetual anxiety they feel. This has been the carer experience for years. Despite progress in carer strategies, respite, carer assessments and family interventions, the basics are still wrong and families are not viewed as a resource. As one carer told us: "*I want to be viewed as a partner, not a problem.*"

Though many people achieve a reasonable quality of life, often it is after many years of distress. Families suffer terribly and it does not need to be this way.

**"Two years ago I would never have believed my daughter would be alive, let alone working, moving into her own flat, cooking supper for us when we visit and doing an evening course. It seems like a miracle!"**  
Family member

## WHAT NEEDS TO CHANGE?

### A family friendly service

Services need to make a fundamental reappraisal of how they treat families and put them at the centre of their thinking and practice. This requires more than the development of a Carers Strategy.

We recommend that organisations providing services take steps to demonstrate how they meet the following criteria:

- Families are viewed as resources, experts, partners in care, not problems.
- Every encounter with the service user should prompt a practitioner to think "what about family?" (Despite the fact it won't always be relevant and not everyone wants them involved).
- Families are actively supported in their caring role - not abandoned to their fears and grief.
- Family interventions and respite breaks are available.
- Helpful and compassionate staff are the norm.
- Families do not experience unnecessary barriers to information sharing - giving their own views or receiving relevant non-personal information.
- There is respect for, and acknowledgement of, the role of long-term carers.
- There is a named key worker and point of contact to access the system in a crisis.
- Family involvement in training practitioners and reviewing services is the norm.

**"Schizophrenia is bad enough as it is for families without the additional burden of having to fight constantly for some recognition from services of the role they play."** Paul Jenkins, Member of the Commission

**We recommend that the Department of Health asks the Standing Commission on Carers to develop a non-bureaucratic system which can be used to assess the quality of support which services provide for families. It should build upon the Triangle of Care initiative which asks all mental health providers to produce action plans which outline how they will ensure carers are effectively supported.**

### Information exchange

We believe that organisations and practitioners should take steps to make information exchange with families the norm. There should be exceptions to protect the rights of people who do not want their families involved, but information from carers should always be considered (as it may indicate a serious risk or deterioration in a person's health which services would be otherwise unaware of).

Refusal to involve families, particularly long-term carers, should be regularly revisited. There is best practice guidance on information exchange based upon research and other resources from voluntary sector providers as well as the Royal College of Psychiatrists (Slade et al, 2007).

We believe there are practical steps which can be taken to help this situation:

- Advance directives should be offered to all people with severe mental illness to help manage treatment preferences when a person becomes unwell.
- Consent to share information should be updated regularly to promote effective communication between practitioner, the person and family members.
- Practitioners should receive training on effective information sharing so they feel more confident to balance clinical judgements over patient rights to confidentiality and to manage risk.
- Carers should always be given a contact point to access the mental health system in a crisis.

**We recommend that all mental health providers should routinely encourage people who use their services to develop an advance directive.**



**“We received evidence from over 1000 families in our online survey and it was very hard to read about all their experiences because of the huge emotional stress that severe mental illness places upon the entire family. Families want better outcomes for their relative or friend. Families also need better support to cope themselves. We know the role of carers and families is acknowledged in guidelines and mental health policy but this does not routinely translate on the ground into appropriate support and information”**

Vanessa Pinfold, Secretariat to the Commission

### Families have a right to receive support to care effectively

Services must do more to recognise the needs of families and provide the support which will enable them to care effectively. This includes support for siblings who are often significantly affected when a brother or sister develops psychosis and for many years afterwards. It should also include help for the children of people with the condition as they may be heavily involved in caring for their parent. This should include access to appropriate:

- Information and interventions.
- Support groups.
- Respite care.
- Family education.

Families need different support at various stages. Personal budgets for carers would give them choice over support and it's important they are properly resourced with systems that aid their use, not hinder uptake.

**We recommend that Clinical Commissioning Groups and local authorities commission an appropriate range of services to support the needs of carers of people with schizophrenia and psychosis including information and advice along with arrangements for respite care.**

## **Surviving schizophrenia by Louise**

“I was a sensitive child, prone to anxiety. I smoked cannabis for the first time when I was just 13, which precipitated the onset of panic attacks. I left home at 16 and struggled emotionally and financially, and at the age of 19 in my first year of University I suffered a psychotic breakdown.

I was sectioned and diagnosed with schizophrenia. I had another breakdown at the age of 25, and was sectioned again, following which I spent several years as a patient at a day hospital. When I was 31 I had a third and final breakdown after the birth of my first child.

That was 12 years ago, and now my husband and I have four children. I have no symptoms of mental illness, and I have been free of psychiatric medication for many years. I manage my anxiety by sleeping and eating well and taking regular exercise. I have also had cognitive behavioural therapy. The support of my husband, and the security that I have found within the family environment, has been invaluable.

I believe that the most important aspect of recovery is hope, and in my opinion the stigma of the label ‘Schizophrenic’ negates hope in the individual. I hope that the Schizophrenia Commission will recommend abolition of the diagnosis and encourage mental health professionals to concentrate instead on treating the symptoms of serious mental illness with compassion and without judgement.”



“

**Louise’s recovery story is testament to the power and survival of the ‘self’ when she was faced with the awful prognosis attached to this diagnosis.**

**She has proved that there can be other routes to wellness from serious mental illness that are founded in hope, strength and self-determination; and that for some, complete recovery from schizophrenia is possible without a long term antipsychotic.**

”



TERRY BOWYER  
MEMBER OF THE COMMISSION

“

**The biggest challenge is the attitude of some professionals.**

**Those working with people who have a severe mental illness should possess the right personal qualities i.e. be caring, non-judgemental, understanding and encouraging.**

”

# WE NEED TO DEVELOP THE WORKFORCE TO DELIVER A NEW MODEL OF CARE

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Supporting service users and their families requires practitioners who bring empathy and compassion to their role. Communication as well as clinical skills are central to good outcomes. Staff need to be kind, caring and compassionate in responding to the needs of individuals and to be able to devise and deliver a flexible package of support in line with the recovery ethos.

**“A little human kindness goes a long way.”**

Voluntary sector provider

**“The opportunity to learn from each individual who has trusted me enough to let me try and help. This learning has helped me to strive to improve the service I manage.”**

CPN and manager

## WHAT WE HEARD IN OUR EVIDENCE

The mental health workforce is made up of very many committed individuals who strive, sometimes in very difficult circumstances, to provide quality support to people living with severe mental illness. This is recognised by service users and their families. In our online survey, people with lived experience and carers were asked to rate the input of practitioners. The most highly rated practitioners for people using services were Community Psychiatric Nurses (CPNs) with 25% of respondents using their single vote for this group followed by 18% for psychiatrists, 12% for support workers and 12% for psychologists.

Families also voted for CPNs (25%), followed by support workers (17%) and psychiatrists (16%). The qualities service users most valued were the ability to empathise and connect, a person's expertise, their ability to provide a safety net, and being treated with dignity, respect and trust. Practitioners themselves also told us of the importance of trust, openness and honesty.

**“I value openness, pragmatism, positivity and I really value their strength of character. I am often in awe at the way these clients can persist in chipping back some of what life offers.”** Community Psychiatric Nurse

The evidence we collected about current perceptions of the workforce was mixed. There were reports of excellent practitioners whose skills and values were greatly appreciated by people and their families but we were concerned by the level of negative feedback we received about the practice and the values of some staff.

**“The family therapist John was something else. Now there was a man with commitment, a passion for his profession, always friendly, respectful and earnest in his approach. We have also experienced the most dreadful arrogance, thoughtlessness and downright unprofessional attitude from some.”** Family member

Some of the greatest criticism was directed at staff working in acute care settings. One particular issue that came up repeatedly was that staff on wards failed to talk to or listen to the people using their services. Some of the same complaints were made of community based staff although we equally heard about strong relationships with a good CPN, care co-ordinator, housing worker or support worker making a major difference.

By contrast, it was striking how frequently Early Intervention Teams were identified as examples of good practice. A key feature highlighted was the holistic and non-judgemental approach – offering hope, encouragement and a positive outlook for the way forward.

We heard a lot of interest from both service users and others about the value of specialist peer workers. There is a developing evidence base for their effectiveness and we believe their use has much to offer in improving the care of people with schizophrenia and psychosis.

With 31% of people only seen in primary care and a further 47% seen only twice a year by psychiatrists, primary care practitioners have a key role to play in the care of people with severe mental illness. Under the new NHS arrangements this is likely to grow. However, we were concerned at the evidence that schizophrenia and psychosis are among the conditions GPs least like to treat. Out of 35 listed conditions, schizophrenia was ranked 35th with depression at 34th. (Album et al, 2008).

We have identified major concerns about the quality of leadership and a lack of clarity at the local level about who is in charge and who is accountable. We believe there needs to be much clearer leadership in acute care units since all too often, service users and families told us that it was quite unclear who was in charge of an acute care unit or that the person theoretically in charge was rarely visible in the ward. In community teams, leadership is equally important for quality provision. There has to be clear information about who is responsible and accountable for a particular aspect of care, and how these people can be contacted.

Dealing with people in the acute phases of schizophrenia is difficult and draining for staff: this is probably one of the most testing of all conditions we ask public servants to handle and requires exceptional human qualities. Staff need a lot of support to function at the optimum level and to remain effective as workers. Many staff are exhausted, ‘burnt out’ and de-motivated and the systems to deal with this often do not exist or are being cut back. Good practice is not celebrated enough and this also affects morale and motivation.

## WHAT NEEDS TO CHANGE?

**“In an era of patient choice, the voice of mentally ill people is still ignored. They should be made a ‘treatment offer’, as others are, and this should be open to negotiation, except where the nature of their illness makes that impossible.”** Jeremy Laurance, Member of the Commission

### Values based practice

Services working with such a vulnerable group need to be grounded with a clear and explicit set of values saying what is expected from staff. Service users and families in their evidence to us were clear about what this should include:

- Treating people as individuals, non-judgementally and with empathy, seeing the person first, not the illness, and acknowledging the human being beneath the illness at all times.
- Demonstrating a genuine understanding of what it is like to live with a severe mental illness and trying to connect with this experience.
- Listening to people and taking seriously the significance of their own accounts of their illness and other events in their lives by giving some credence to the meaning they attach to it.
- Being prepared to go the extra mile and, in particular, helping people negotiate the next steps of the system by providing useful support, guidance and information.
- Understanding the cultural dimensions of mental illness and being sensitive to different explanations.



**“The NHS for too long has failed to give sufficient priority to meeting the needs of people with mental illnesses such as schizophrenia and psychosis. In addressing this we need a shared approach to service delivery between general practitioners, psychiatrists and other mental health professionals working together.”**

Clare Gerada, Member of the Commission

- Being hopeful, positive and encouraging with staff looking for the potential in everyone regardless of how severe the illness may be.
- Providing opportunities for people to empower themselves, taking back control over their lives, and adopting self-management strategies promoting wellbeing.

We believe that all services should follow this value based practice. Guidance on this has been set out by the Centre for Mental Health in their publication “Whose values?” and a helpful set of example values has been produced as part of the IAPT programme for people with severe mental illness.

**We recommend that all providers of mental health services should develop, in consultation with people who use their services and their families, a set of values for how care and treatment should be provided. These values should be promoted in communications with service users and carers and provide a reference point for validating the quality of services.**

### Recruitment and recognition

How staff are recruited is crucial. Traditionally, the greatest emphasis has been placed on the clinical and technical skills of staff. Important though these are, we believe much greater emphasis must be placed on assessing the values a person brings to a role and to other skills like communication. Service users and carers can have a vital role in the recruitment of staff.

We think it should be mandatory for all systems of appraisal and recognition in mental health services to include feedback from service users and carers. This should include senior awards such as Clinical Excellence Awards and the appraisals of senior managers including Chief Executives.

**We recommend that all organisations providing mental health services should review systems for the recruitment and reward of staff to ensure they better reflect the attributes valued by service users and carers. Organisations should ensure that service users and carers are involved in processes for staff recruitment.**

### Strengthening the contribution of primary care

Primary care should play a key role in supporting people with chronic psychosis and their families but GPs and other primary care practitioners generally lack confidence in this area of care. We think there is merit in the Royal College of General Practitioners (RCGP) idea of developing integrated teams covering groups of practices bringing together primary care practitioners and specialists to manage the needs of people with mental illness in the community. We also support the RCGP’s plans to extend the training of GPs with a specific focus on improving their skills in managing people with severe mental illness.

**We recommend that Clinical Commissioning Groups explore the scope to commission integrated community teams bringing together primary care and specialist staff to support people with mental illness in the community.**

### **Training and Development**

Professional and other educational bodies should consider the implications of our findings for their training curricula. There is a particular need to address gaps in GP and other primary care professionals' skills in working with people with schizophrenia. We strongly support the RCGP's campaign to secure agreement for an additional year of GP training and agree that the needs of people with severe mental illness should be a key focus for this.

The exposure of medical students to psychiatry has unfortunately declined over the last decade and needs to be radically overhauled to ensure "parity of esteem" between physical and mental illness. Medical students need to spend more unbroken time on psychiatric placements rather than the "one day a week" model which is all too common and doesn't give them the opportunity to make relationships with either service users or staff. Initiatives such as summer schools and psychiatric societies for the most interested students are valuable and need to be expanded.

Placements should cover a range of conditions but should include time working with people with severe mental illness. Nurses also need better induction into mental health and we would like to see the Nursing and Midwifery Council place greater emphasis on mental health to ensure that general nurses are equipped with the skills to support people with mental illness, and that practice nurses have enhanced training regarding severe mental illness.

We also see a major need to invest in training which builds up the skills of staff working directly with people with schizophrenia in delivering psychological interventions. This includes expanding capacity to deliver formal programmes such as CBT and Family Therapy but also improving the ability of all front-line staff to use psychological skills to improve the quality of their interactions with people with schizophrenia. Resources such as Star Wards' Talk Well can help support staff to develop better skills in communicating with people in acute care and other settings. People with lived experience of schizophrenia and their carers have a key role to play in the delivery both of initial and subsequent training of staff.

**We recommend that professional and educational bodies should review their curricula in the light of our recommendations. We strongly support the RCGP's recommendation to extend GP training in respect of mental illness. We recommend that Health Education England and the General Medical Council should urgently review how medical students could spend more continuous time in their psychiatric placements and have greater emphasis placed on mental health throughout their training and that Deans of Medical Schools should positively promote an interest in mental health.**

### **Leadership**

We believe action needs to be taken to ensure that there is clear leadership and accountability for the delivery of outcomes in acute care and community services.

**We recommend that the NHS Confederation Mental Health Network works with its membership and other stakeholders to develop a model of better leadership and accountability for acute care and community services.**

# Schizophrenia and psychosis: features of a good service

Many people with severe mental illness lead productive and happy lives and many more could do so with better services. Taken together our recommendations would improve outcomes by creating services with the following characteristics:

- Clear leadership, with clinicians and managers taking responsibility for achieving positive outcomes for the people in their care.
- Early intervention and strong preventive action.
- Reliance on evidence (we know ‘what works’) and appropriate resources.
- Integration across primary, secondary and social care with continuity of care and well-managed transition and discharge planning.
- Staff listening to people’s experiences, acting with compassion and delivering a hopeful message at all times, focussing on the potential for recovery.
- Shared decision-making and choice – professionals, service users and, where appropriate, families involved in decisions over care and treatment.
- Psychological and physical health interventions available and promoted assertively, starting on acute wards.
- Up-to-date training to ensure staff have a good understanding of the latest research on schizophrenia and psychosis – biological, psychological and social.
- Treatment settings that feel safe, welcoming and are therapeutic places to be.
- Emphasis on learning and development, including self-management strategies, for people to be best able to cope and take control of living with a severe mental illness.
- Family members, where appropriate and particularly in the case of long-term carers, viewed as partners and given respect and support.
- Much better personalised prescribing and discussion of side effects with the involvement, where appropriate, of specialist pharmacists.
- Use of minimum necessary doses of antipsychotics, and continuing dialogue about the pros and cons of reducing, or where appropriate, stopping this medication.
- Greater choice of treatment and more opportunity to have a second opinion or different psychiatric team.
- Better promotion and use of ‘advance directives’.
- People with “lived experience” of psychosis employed as part of the professional workforce.
- Services reflecting the different needs of people from BME communities.
- Much more cautious use of the diagnosis schizophrenia and use of the more general term psychosis at least in early stages of illness.
- Full consideration given to all the needs of the person including employment and suitable housing.
- Active community involvement to support recovery and reduce stigma and isolation.

# THE COSTS OF SCHIZOPHRENIA

The Commission worked with researchers at the London School of Economics to review the 'cost of schizophrenia'. This is no simple task. Modelling lifetime cost is challenging because the courses and outcome vary so widely. Ending up in secure care for 20 years costs far more than early intervention and discharge to primary care with return to full employment.

The prevalence of schizophrenia is estimated at 0.5%. We estimate that there are 220,000 people living in England with the condition. Broadly this group is supported in the following settings:

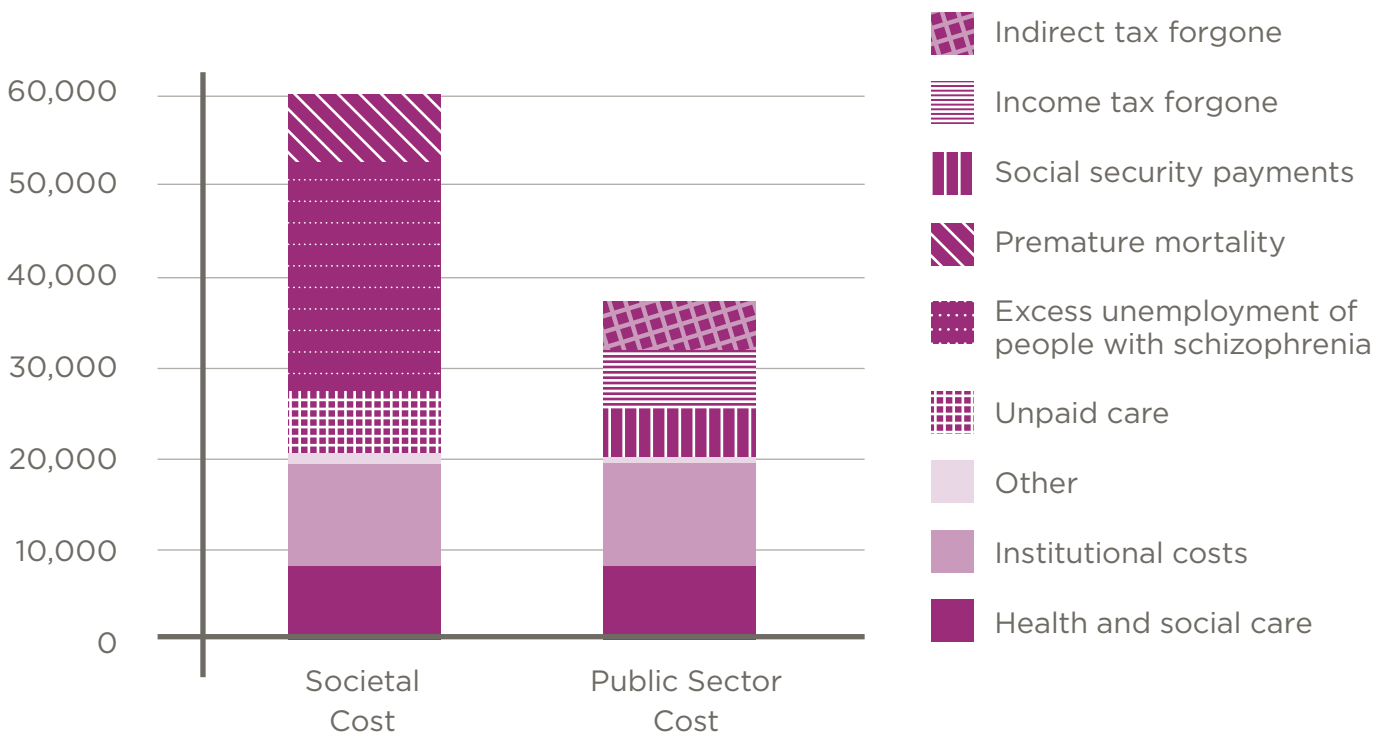
- 4% in prison.
- 2% in secure hospitals.
- 5% in acute care units under a Mental Health Act section.

- 9% in acute care units admitted voluntarily.
- 49% under the care of secondary mental health services.
- 31% solely under the care of the primary care team.

There are very significant economic consequences for many parts of society, especially individuals themselves and their families. In England the cost to society is estimated at £11.8 billion (£60,000 per individual with schizophrenia) per year and the public sector cost £7.2 billion (£36,000 per individual with schizophrenia) per year.

Around one third of societal costs are accounted for by direct expenditure on health and social care, provided both in institutions and in the community.

**Figure 1: Annual costs of schizophrenia to society and the public sector (£ per person with schizophrenia, 2010/11 prices)**







**“Bringing the information together for this report has been challenging. It will be clear from the accompanying LSE report on the cost of schizophrenia that there are areas where we still know little about the costs of delivering services and even less about the longer-term economic impacts. Nevertheless, there is robust evidence around some interventions, making a strong economic case for change. I hope that the work of the Schizophrenia Commission can drive forward some of the changes required to improve quality of care and quality of lives”.**

Martin Knapp, Member of the Commission

More than a half is incurred as a result of the lost productivity of people – both through unemployment and premature death. The final proportion of costs – informal care costs – are incurred by the families and carers.

## WHAT NEEDS TO CHANGE?

We firmly believe that over time the proportion of health and social care resources committed to mental health services must increase. It is scandalous that mental health conditions which account for 23% of the disease burden in England command only 13% of the NHS budget (Layard et al, 2012).

The current budget, however, could be spent much more effectively to improve outcomes for people with schizophrenia. As well as more general programmes to review the efficiency of current services, there are four areas for commissioners at a local and national level to focus on:

- The use of secure care – we believe it would be possible to reduce the number of secure beds with savings redirected to improving community based provision.
- Better use of acute care facilities in some areas where it is combined with investment in community based alternatives to admission.
- The medication budget where modest savings could be made through better prescribing practice.
- Furthering investment in interventions where there is strong evidence that they reduce the probability of an acute care admission. Such interventions include Early Intervention, IPS (Intensive Placement and Support), Family Therapy and CBT.

Specifically we believe that it should be possible to identify in a period of five years the scope for a significant reduction in what is spent on secure care. Any savings must be ring-fenced and reinvested in improving community based provision which helps keep people out of hospital and the secure system.

There are eight treatment areas where the evidence base suggests that increased investment will generate cost savings through reducing the probability that an individual will need to be admitted to hospital. Less is known about peer support workers but early work predicts they will generate savings, and further work on costs is required to establish this evidence base.

The eight promising cost saving treatment areas are:

- Early intervention services.
- Individual placement and support services to help people into employment.
- Family therapy.
- CBT for psychosis.
- Physical health interventions.
- Tackling substance misuse using psychological therapies including motivational interviewing.
- Addressing homelessness using targeted interventions.
- Crisis resolution teams.
- Peer support workers.
- Advanced treatment directives.

# MAKING CHANGE HAPPEN

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The conclusion of our inquiry is that, despite some important areas of progress, the current system of care and support for people with schizophrenia and psychosis, and their families, is failing both them and the taxpayer. While there have been positive developments in areas such as early intervention, crisis resolution teams and crisis houses, recovery colleges, direct payments and peer specialists, it is disheartening to identify issues such as levels of coercion, poor physical health, access to talking treatments and participation in employment, where outcomes remain unacceptable.

We have highlighted in our report a considerable number of areas which require attention and also what could be done to improve matters. But change will not happen on its own, especially when finances are tight. There is a need for leadership nationally and locally if the current situation is to be improved. Fortunately, we do know what can make a difference – the situation would be much improved if only we applied best practice everywhere, used evidence-based interventions and listened to service users about what they feel would make the most difference to their recovery. The Commission feels hopeful that change can be achieved with strong visionary leadership and we are encouraged by the recognition from managers and practitioners that things do need to improve. Much of what we have identified about people with schizophrenia and psychosis will be true of other groups using secondary mental health services and we believe our recommendations will benefit them.

## **PARITY OF ESTEEM FOR MENTAL HEALTH IN A TIME OF AUSTERITY**

The Government's Mental Health strategy "*No Health without Mental Health*" sets an expectation that there should be parity of esteem between mental and physical health services. While we welcome this ambition and the fact that it has been subsequently enshrined in the Health and Social Care Act, our investigation makes it clear that we are still a million miles away from this being the case for people with schizophrenia and psychosis. If "parity of esteem" is to be more than an empty rhetorical phrase, the Government needs to use the levers within the new health and social care system to prioritise mental health and secure improvement for this seriously disadvantaged group. We do know what is needed but we don't do it in most places.

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This will be a major litmus test for the NHS Commissioning Board both as a commissioner of services and in its role in holding local commissioners to account. It must nail its colours to the mast and address the historic bias which senior NHS leadership has shown in giving low priority to issues relating to serious mental ill-health.

The Commission was deeply concerned at the news that in 2010/11 the NHS mental health budget had fallen by £150 million – the first decline in 10 years. While we believe some of the current resources for services could be better used, it is crucial that overall mental health budgets are protected.

But parity of esteem is about much more than money. It will only be possible if there is a more open public debate about mental health. As a society we need to ‘open up’ about mental illness and start talking about it, for it is a subject that affects us all. Most of us know someone with serious psychosis or diagnosed as having schizophrenia as 1 in 100 people are affected at some point in their life, and many of us have family or close friends who suffer. There are some encouraging signs with the impact of anti-stigma programmes such as Time to Change and the brave decision by some celebrities to talk about their serious mental illness. The media has a crucial role to play in changing the degrading stereotypes of people with schizophrenia and psychosis and instead publicising the poor state of provision and the blighted lives led by people with the condition.

## RETHINKING RISK

The Commission fully accepts that there is a need for the provision within the mental health system to provide care for some people under compulsion or in a secure setting when they present a risk to themselves or others. However, with rates of coercion increasing and £1.2 billion (or more than 1% of the entire NHS budget) spent on secure care, we believe that the obsession with risk has gone too far. We believe the time has come for an urgent rethink of how resources are spent in the secure sector. We must ensure that secure provision represents a necessary measure for the minority of people with severe mental illness who need it and not a testament to our failure to provide timely and effective interventions in the community for the hundreds of people who end up there unnecessarily or who could transfer to other forms of care once their condition is stabilised.

## JOINING UP HEALTH AND SOCIAL CARE

People with schizophrenia and psychosis and their families are ill-served by the artificial divide between health and social care. Interventions such as good housing, employment and activities that promote wellbeing are fundamental to recovery. Health and Wellbeing Boards will have a key role in monitoring the overall provision to support people in the community, because it is in the community that these problems develop and where they need to be addressed.

Government needs to recognise that the cuts falling on social care funding are beginning to erode the infrastructure of community care. This will have a significant impact on the lives of people with schizophrenia and psychosis and will create additional pressure on expensive hospital services. Budgets to

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address the needs of people with severe mental illness need to be pooled so that the systems of the NHS and local councils do not work in opposition and the most economical and effective arrangements are made irrespective of organisational boundaries.

We are also concerned about the current obstacles to implementing personal health budgets and self-directed social care but warmly welcome the commitments to extend this made in the Government's Social Care Bill.

## COMMISSIONING

We welcome the establishment of Health and Wellbeing Boards with powers to improve the quality of services and build on effective initiatives like the EIP services. The Commission recommends that there are specific individuals on Health and Wellbeing Boards with a remit for mental health and that all Clinical Commissioning Groups should have a specialist Mental Health Commissioner, whose role will be to give them sound clinical advice about which services are commissioned. It is essential that the Commissioner has advice from a practitioner with a background in mental health and from those with experience of managing the complexities of mental health services.

The Commissioner needs the skills to create greater accountability and transparency in the mental health system. This will ensure that there is a greater ability for commissioners to hold mental health providers to account over the services they provide. National groups such as the Joint Commissioning Panel established by the Royal College of Psychiatrists and the Royal College of GPs can play a key role in developing clear guidance for local commissioners.

## EVIDENCE BASED MANAGEMENT

In our evidence, we have heard major frustrations from service users, families and practitioners about how the system is getting in the way of providing effective support. We heard particular concerns about organisational arrangements which mean there is no continuity of psychiatric care in acute care units or between units and the community and about the impact of constant service reorganisation. In the worst instances, service users are passed from one team to another having to repeat their story of distress to an entirely new person each time. Major changes to the system are needed but they should only be introduced after piloting: and only after properly involving the people these changes would affect – namely the people who access services and their families as well as practitioners.

Senior leaders in Trusts and other organisations need to know at first hand what is happening in front-line services. We think it would give the right signal if every Chair and Chief Executive, and ideally all Board members, committed to spend at least a day each year in one of their acute care units.

## PROFESSIONAL LEADERSHIP

We believe there is great need for better professional leadership. Some of the standards of practice we encountered in our investigation, for instance in relation to prescribing, are unacceptable.

We have also highlighted concerns about deficits in kindness and compassion in some services. This must be addressed. Some of the answers lie in how we recruit and reward staff. Some of them lie in how we address the staff's own needs and address issues of "burn out". The ongoing professional development

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of staff requires immediate attention. We are concerned that a crucial group - nurses (who hold the system together) - lack clear continuing professional development opportunities to further their skills and become more effective workers.

## **CO-PRODUCING SERVICES WITH SERVICE USERS AND FAMILIES**

**“We have come a long way. I can’t believe that 20 years ago my view would count for anything.”** Service user

Finally, things will only get better if we give much greater authority in the mental health system to services users and families, and acknowledge that their lived experience is of paramount importance and should be ‘core’ to driving through much needed change. Our investigation highlights the importance of people’s own understanding of the experience they are undergoing and their insight into what is most likely to support their recovery.

In the last 20 years the user movement has grown significantly across England. It has developed both as a campaign force for change, pushing services to do things differently, and as an educator, helping people make sense of their own experiences and explaining it to others. In this way, the user or survivor movement has made a major contribution to the development of mental health services.

We believe this must go further. Practitioners must genuinely embrace the principles of shared decision-making in the individual relationships they have with people who use their services and service users must also have greater influence and control over priorities in service provision.

Despite the concerns we have identified, we know that there are highly successful services and committed staff working tirelessly in very difficult circumstances. We are optimistic and believe improvement is entirely possible. It will, however, need recognition and leadership from all parts of the system to make it happen. The current state of affairs, however, is not acceptable and we now need to make fundamental changes to our system – listening to the voice of the people with schizophrenia and their families as well as to the professionals.



**Change won’t take place just with tinkering with the system. Significant improvement will only come about if there is a fundamental change in the way in which support is organised which shifts from one where the professional view predominates to one where the person using the service is in as much control as possible.**



Jonathan Phillips, Member of the Commission



Professor Sir Robin Murray, January 2012 at our Schizophrenia Commission first evidence gathering event held at the Imperial War Museum in London.

# SUMMARY OF OUR RECOMMENDATIONS

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## THE GOVERNMENT

1. We commend the Department of Health, the Big Lottery Fund and Comic Relief for investing in Time to Change ([www.time-to-change.org.uk](http://www.time-to-change.org.uk)) and recommend continued investment in anti-discrimination programmes and other public education initiatives that deliver accurate messages about mental health and mental illness with the aim of changing attitudes and behaviour. These need to address the elements of stigma and discrimination which are specific to people affected by schizophrenia and other psychotic illnesses.
2. We recommend that the Department of Health, with involvement from the Ministry of Justice, requires the NHS Commissioning Board to develop a national commissioning strategy for secure care with the aim of rationalising definitions of security and establishing recovery-focused care pathways through secure care. Savings identified as a result of this exercise should be reinvested in strengthening community based provision.
3. We recommend that the Department of Health works with representatives of the pharmaceutical and research communities to increase investment in research for new and improved medications for psychosis.
4. We recommend that the Department of Health, as part of its current review of shared decision-making, commits to giving people using mental health services an element of choice as to where they are treated, with a particular focus on guaranteeing a right to a second clinical opinion and allowing people and families a bigger say in choosing a lead professional for their care.
5. We recommend that the existing nursing workforce, particularly in acute units, should be better trained to deliver simple talking and supportive therapies and that the Department of Health, in consultation with other stakeholders, should introduce a maximum waiting time for access to psychological therapies for people with severe mental illness which is embedded in the NHS Constitution. We recommend that the Department of Health and NHS Commissioning Board should agree arrangements for continuing the IAPT programme for people with severe mental illness beyond March 2013.
6. We recommend that, as a matter of urgency, the Department of Health develops indicators for measuring reductions in the excess mortality levels among people with severe mental illness.
7. We recommend that when the Government sets the national social care eligibility criteria, guidance ensures that people with fluctuating conditions who need on-going support to remain independent do not lose services.
8. We recommend that the Work Capability Assessment process is amended for people with schizophrenia and psychosis to require the Department for Work and Pensions to seek information from health professionals to guide decisions rather than requiring potentially vulnerable people to navigate complex systems in order to provide it themselves. The same principle should be built into plans relating to any qualifying assessment for the new Personal Independence Payment.
9. We recommend that the Department of Health and Ministry of Justice ensure that the commitment to establish diversion and liaison teams in every area by 2014 is followed through. Such teams, working

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with mental health services, the police and sentencers, should focus on helping to reduce the number of custodial sentences for people with psychosis where neither their offence nor the risk they present to others warrants it.

10. We recommend that the Department of Health asks the Standing Commission on Carers to develop a non-bureaucratic system which can be used to assess the quality of support which services provide for families. It should build upon the Triangle of Care initiative which asks all mental health providers to produce action plans which outline how they will ensure carers are effectively supported.

## NATIONAL BODIES

11. We recommend that the Royal College of Psychiatrists and the Department of Health should regularly repeat the National Audit of Schizophrenia on prescribing and make public its results so that not only Mental Health Trusts and providers but also service users and carers can see the performance of local services. Clinical Commissioning Groups should only commission mental health providers who are signed up to the audit and who provide plans for improving practice in response to any outlier results.
12. We recommend that the Royal College of Psychiatrists works with other stakeholders to define higher standards for the training of prescribers. Prescribing modern antipsychotic drugs, especially in combination and in dosages that can be off-licence, is a specialist skill and as such should only be undertaken where the prescriber has the knowledge, experience and competence to do so.
13. The Commission recommends that the Academy of Medical Royal Colleges, the Royal College of Nurses and the Health and Care Professions Council should place greater emphasis on physical health in severe mental illness in the training of all doctors, nurses and mental health practitioners. Mental health practitioners, in particular nurses, should be able to demonstrate competence in providing basic physical health care and progression through training should be dependent upon this.
14. We recommend that the NHS Confederation Mental Health Network works with its membership and other stakeholders to develop a model of better leadership and accountability for acute care and community services.
15. We recommend that professional and educational bodies should review their curricula in the light of our recommendations. We strongly support the RCGP's recommendation to extend GP training in respect of mental illness. We recommend that Health Education England and the General Medical Council should urgently review how medical students could spend more continuous time in their psychiatric placements and have greater emphasis placed on mental health throughout their training and Deans of Medical Schools should positively promote an interest in mental health.
16. We recommend that Public Health England develops a preventative strategy for psychosis including promoting protective factors for mental wellbeing and reducing risks such as cannabis use in early adolescence. This area needs to be addressed within the Public Health Outcomes Framework.



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17. We recommend that Public Health England and the NHS Commissioning Board work together to ensure that mental health and substance misuse services are commissioned to provide people with co-occurring severe mental illness and drug or alcohol misuse with integrated care and treatment to support their recovery.
  18. We also recommend Public Health England leads a high profile educational campaign pointing out the risk of heavy cannabis use at an early age, particularly of high potency forms.
  21. We recommend that Health and Wellbeing Boards ensure there is a strategy in place which specifically addresses the needs of minority ethnic groups in their communities. The strategy must include an emphasis on mental health promotion as well as providing personalised care which must be culturally competent.
  22. We recommend that all Clinical Commissioning Groups commission Early Intervention in Psychosis services with sufficient resources to provide fidelity to the service model. It is crucial that the NHS Commissioning Board holds local commissioners to account for this and we recommend that early intervention services are included in the NHS Commissioning Outcomes Framework.

## COMMISSIONING AND STRATEGY

19. A radical overhaul of acute care is needed and only units which patients would recommend to family and friends should be seen as “good enough”. We recommend that the NHS Commissioning Board introduces as soon as possible a “friends and family” test for acute mental health units which reflects the issues of concern highlighted in this report and in previous work such as Mind’s report on acute and crisis care “Listening to Experience”. We recommend that the Department of Health asks the CQC to reinstate its annual survey of the standards of inpatient care to provide an independent view on the quality of services.
20. We recommend that Health and Wellbeing Boards ensure the housing needs of people with severe mental illness are adequately addressed.
23. We recommend that Clinical Commissioning Groups commission services to extend the successful principles of early intervention to support people experiencing second and subsequent episodes of psychosis.
24. We recommend that Clinical Commissioning Groups and providers explore alternatives to admission as part of their plans for the development of acute care and crisis services.
25. We recommend that Clinical Commissioning Groups should ensure that they commission services for people with schizophrenia and psychosis in line with NICE and other good practice guidelines, including CBT for psychosis.
26. We recommend that Clinical Commissioning Groups and providers work together to deliver a range of preventative, secondary and acute care services underpinned by cultural competency principles to meet the needs of diverse local populations.

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27. We recommend that Clinical Commissioning Groups and local authorities should ensure that the needs of people with schizophrenia and psychosis who are homeless are captured in their Joint Strategic Needs Assessment and reflected in local commissioning plans.
  28. We recommend that all local authorities, NHS Trusts and Clinical Commissioning Groups should integrate and actively promote personal budgets, where appropriate, for people with schizophrenia and psychosis and ensure that adequate support is available for those who choose to manage a direct payment. Local Councils should report specifically on their progress in introducing self-directed support for people with mental health problems and should set themselves stretching targets to improve their performance. Far more integration between personal health and social care budgeting is required to deliver value for money.
  29. We recommend that Clinical Commissioning Groups and local authorities commission an appropriate range of services to support the needs of carers of people with schizophrenia and psychosis, including information and advice along with arrangements for respite care.
  30. We recommend that Clinical Commissioning Groups explore the scope to commission integrated community teams bringing together primary care and specialist staff to support people with mental illness in the community.

## MONITORING AND REGULATION

31. We recommend that the Press Complaints Commission or its successor body should work with mental health organisations to define standards in the reporting of violent crime involving people with a mental illness.

## MENTAL HEALTH PROVIDERS

32. We recommend that psychiatrists are very cautious about making a diagnosis of schizophrenia, in particular after a first episode of psychosis; at that point making such a diagnosis may do more harm than good. The term psychosis, though far from perfect, does not convey the same pessimism and fear.
33. We recommend that all mental health providers should ensure that people with schizophrenia and psychosis (in hospital and the community) are aware of their right to request a review of their medication including, where appropriate, access to a specialist pharmacist, and are encouraged to exercise it in practice.
34. We recommend that all mental health providers should review opportunities to develop specific roles for peer workers.
35. We recommend that each mental health provider promotes the use of clinical tools to support the physical health needs of people with schizophrenia or psychosis on antipsychotic medication, and ensure that these are visible in every mental health ward in the country. These include the Lester UK Adaptation – Positive Cardiometabolic Health Resource.

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36. We recommend that each mental health provider works with the local Director of Public Health to ensure that there is targeted smoking cessation provision for smokers with schizophrenia and psychosis, with guidance from Public Health England.
  37. We recommend that all NHS Mental Health Trusts and other mental health providers invest in recovery-focused whole system transformation and development for staff such as ImRoc.
  38. We recommend that all NHS Mental Health Trusts and other providers adopt the Individual Placement and Support (IPS) model and ensure that employment support is effectively integrated with clinical services. We believe such support may be best provided by voluntary sector organisations being co-located with clinical teams. Outcomes will also be improved where Mental Health Trusts work closely with Work Programme providers.
  39. We recommend that all mental health providers should routinely offer to people who use their services the opportunity to develop an advance directive.
  40. We recommend that all providers of mental health services should develop, in consultation with people who use their services and their families, a set of values for how care and treatment should be provided. These values should be promoted in communications with service users and carers and provide a reference point for validating the quality of services.
  41. We recommend that all organisations providing mental health services should review systems for the recruitment and reward of staff to ensure they better reflect the attributes valued by service users and carers. Organisations should ensure that service users and carers are involved in processes for staff recruitment.

## RESEARCH FUNDING BODIES

42. We recommend that the National Institute for Health Research and the Medical Research Council develop a new strategy for increasing investment in research into the causes and treatment of psychosis with a focus on bringing together biological, psychological and social perspectives.



# THE COMMISSIONERS

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<b>Professor Sir Robin Murray</b> (Chair)	Professor of Psychiatric Research at the Institute of Psychiatry. Elected a Fellow of the Royal Society (FRS) in 2010.
<b>Terry Bowyer</b>	Peer Specialist, Dorset Mental Health Forum who has a diagnosis of paranoid schizophrenia.
<b>Dr Alison Brabban</b>	Consultant Clinical Psychologist and Clinical Lead in the Early Intervention in Psychosis service in Tees, Esk and Wear Valleys NHS Foundation Trust. National Advisor for Improving Access to Psychological Therapies (IAPT) for Severe Mental Illness.
<b>Neil Carr</b>	Chief Executive of South Staffordshire and Shropshire Healthcare NHS Foundation Trust.
<b>Dr Clare Gerada</b>	Chair of the Royal College of General Practitioners.
<b>Paul Jenkins</b>	Chief Executive of Rethink Mental Illness.
<b>Professor Martin Knapp</b>	Professor of Social Policy at London School of Economics and Political Science and Professor of Health Economics in the Centre for the Economics of Mental Health, King's College London.
<b>Jeremy Laurance</b>	Health Editor of The Independent.
<b>Liz Meek</b>	Chair of the Centre for London who has a family member with schizophrenia.
<b>Jonathan Phillips</b>	Former Director of Adult Social Services, Calderdale Council. Independent Chair of North Yorkshire County Council Safeguarding Adults Board.
<b>Dr Vanessa Pinfold</b> (Secretariat)	Research Fellow, Rethink Mental Illness and Chair of the McPin Foundation.
<b>Dr Shubulade Smith</b>	Consultant Psychiatrist at the South London and Maudsley NHS Foundation Trust and Clinical Senior Lecturer at the Institute of Psychiatry, King's College London.
<b>Professor David Taylor</b>	Director of Pharmacy and Pathology at the Maudsley Hospital, Professor of Psychopharmacology at King's College London and Honorary Professor at the Institute of Psychiatry.
<b>Yvonne Stewart-Williams</b>	A campaigner and an activist who works with complex needs and mental illness and has a schizo-affective disorder diagnosis.

# ACKNOWLEDGEMENTS

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We are grateful to everyone who has contributed to the work of the Commission, particularly those who gave evidence in person at our events and submitted material through our surveys.

The work of the Commission was supported by an unpaid intern, Annaliese Grist who worked with us for 9 months and also Alistair Grace; a masters student and psychiatrist from Canada, Sabina Nagpal, who carried out her dissertation project with the Commission; an unpaid intern working over the summer 2012 with Professor Martin Knapp at LSE to produce a report on the costs of schizophrenia, Alison Andrews; and Daniel Lombard, also on placement at LSE, who reviewed published literature reviews for us. We are also grateful to the artists who shared their work on our website.

Finally, thank you to all the staff at Rethink Mental Illness who have supported the Commission and to the Board of Trustees who made available funds for this independent Commission to carry out its work.

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The Schizophrenia Commission is an independent group set up and funded by Rethink Mental Illness (Registered charity number 271028).

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**This report should be referenced as:**

The Schizophrenia Commission (2012) *The abandoned illness: a report from the Schizophrenia Commission*.  
London: Rethink Mental Illness.