

rethink

fair
treatment
now

Better outcomes, lower costs
in severe mental illness

Executive summary

Mental illness costs the nation around £33.75 billion a year, but less than a quarter of that goes on health services¹, with the majority falling to non-health services. The police, benefits system, housing services and others often have to pick up the pieces when things go wrong.

There are over 1.5 million people in England with severe mental illnesses like schizophrenia, bipolar disorder, personality disorder and severe depression. Many are not getting the cost-effective, evidence-based treatment they need. As a result of not getting this treatment, people with severe mental illness:

- Die up to 10 years younger compared with the rest of the population – not just from suicide but from preventable physical illnesses
- End up in prison, or homeless, because they have not received cost-effective treatments which could have prevented this
- Are without meaningful occupations, and more likely to depend on welfare benefits, because they haven't had the right support

Health professionals recognise that mental health treatment is at an unacceptably low standard. We surveyed 251 GPs, and found:

- Only 1 in 3 GPs are confident in the quality of secondary mental health services available
- Only 29% are confident that the patient will be supported to recover long term
- Only 1% of GPs say they are 'very confident' that a patient with psychosis will not come to harm while awaiting their secondary care assessment

Severe mental illness must be integral to the coalition government's health policy if we are to deliver the savings needed in criminal justice and benefits bills. Mental health is currently excluded from initiatives such as the Choice agenda and Payment by Results, but including mental health could help deliver better services and better value.

The development of a new outcomes-based NHS framework is a golden opportunity to reduce deaths and improve recovery rates. For severe mental illness this means reducing suicide and early death from physical health conditions, cutting emergency readmissions and shortening the duration of untreated psychosis. It means increasing the information that carers have to support them, improving employment rates, improving crisis care and working for greater public acceptance of mental health issues.

Introduction

At an estimated £33.75 billion a year, mental illness represents a significant national economic burden. But the impact isn't only on the NHS. These costs often accrue because fair, cost-effective treatment hasn't been available in the early stages, resulting in expensive crisis admissions (and readmissions) to hospital, worklessness, homelessness, substance misuse and criminal justice problems. When the system doesn't meet the treatment needs of people with mental illness, they often become more unwell, for longer. That increases the pressure on families and carers as well as other public services. It's a false economy and the human cost is inestimable. But it doesn't have to be like this. There's a wealth of evidence suggesting that decent mental health treatment produces better long-term outcomes, for less money.

No less than half of the wider cost of mental illness – £17 billion, is related to severe mental illnesses, such as schizophrenia, bipolar disorder and personality disorder.² There are at least 1.5 million people living with severe mental illness in Britain today, and they're amongst the most vulnerable in our society.³

The Mental Health National Service Framework made great strides for mental health service provision, developing community services such as Crisis Resolution and Home Treatment Teams, and Early Intervention services.⁴ With this ten year framework drawing to a close in 2009, we have already seen these same mental health services being targeted for spending cuts.⁵ It is essential that future plans for mental health ensure adequate provision during this time of financial hardship and beyond.

People with severe mental illness diagnoses get a consistently raw deal in the health system – being frequently denied access to psychological therapies, having physical health overlooked and being totally excluded from the Choice agenda.

So it's perhaps unsurprising that they have some of the worst health, social and economic outcomes in society. Many individuals and their families and carers are left in distress with relatively little support, and sadly, many let down by the system are driven to take their own lives. Indeed, 10% of people with schizophrenia will die by suicide.

Even where suicide rates are excluded, people with severe mental illness have a significantly reduced life expectancy, due to preventable physical illnesses.





Non-specialist health professionals also lack confidence in mental health services. We surveyed 251 GPs and found that only 1% are 'very confident' that a patient with psychosis will not come to harm while awaiting support from specialist mental health services. More than 90% are confident in services for cancer, diabetes and cardiovascular disease, yet only around half say the same for services for psychosis and depression.

GPs also report that they lack the expertise to commission services for mental health. This is a serious cause for concern when there are moves toward increasing GPs commissioning responsibilities. When we asked GPs if they felt well-equipped to commission services, 75% said 'Yes' for diabetes, 76% for asthma and 74% for smoking cessation. Only 31% said 'Yes' for mental health.

In 2009, the NHS Confederation warned of the costs of 'shortcut commissioning' of mental health services:

“Significant disinvestment in mental health services would, without doubt, deliver immediate, medium and long-term pain for the NHS and other public services. Most importantly, it would have a negative impact on people experiencing mental distress and illness, as well as their carers and families. Such shortcut commissioning would not only increase their burden, but would ultimately result in a larger economic burden for the nation.”⁶

Services for people with severe mental illness are already fragile, underfunded and often not offering evidenced, cost-effective treatment. Now, with resources stretched and with mental health spending less transparent due to the lack of a national tariff, the frontline services that do exist for those with severe mental illness are likely to be at greater risk of cuts. Rethink knows that any further reduction in health services for this most vulnerable group will have a devastating human impact, and in the end, will only cost the country more.

But there is hope: when people with conditions like schizophrenia and bipolar disorder do get evidence-based treatment and fair and equal access to health services, they stand a good chance of recovery.

Fair treatment does not need to cost more. In 2008, the King's Fund found that immediate savings of up to £9 million could be made if early intervention services were provided to 60% of new cases of schizophrenia. This could increase to £44 million if coverage were 100%. At this moment, when scarce public money must be spent as cost-effectively as possible, we simply can't afford to ignore severe mental illness and miss this golden opportunity to put things right.

We firmly believe there is cause for optimism; we know there are treatments that are effective and give people with conditions like schizophrenia and bipolar disorder a real chance of recovering a good quality of life. This report shows how and why we need fair treatment now – fair for people with severe mental illness, fair for their families and fair for the taxpayer.

What's not fair?

Rethink works with thousands of people who use mental health services every year, as well as family members and friends who provide unpaid (and often unrecognised) care. We frequently hear about distressing experiences; the inequality of access to services and neglect they face makes them one of Britain's most vulnerable groups. National policy and guidance is often well-meaning, but we know that the reality can be vastly different.

The evidence points to grave inequalities in health and mortality, little to no access to ongoing healthcare and repeated involvement with the criminal justice system. This places enormous strain on families and carers, and ultimately results in an increased economic burden for everyone. In a society where the health and wellbeing of families and communities are valued, we cannot allow a whole group of vulnerable people to remain so neglected.

Rethink conducted a survey of 441 mental health service users and 111 carers and found that, in the last two years, many are still missing out on evidence-based, cost-effective treatments.

Only 16% of service users received all the **recommended interventions** applicable for their diagnosis.

Less than two thirds of mental health service users had been offered **psychological therapy** (61%) as recommended by NICE. Less than half of carers reported this being offered (47%). Only 51% of people with schizophrenia or bipolar disorder have been offered psychological therapy.

Only one in three mental health service users had been offered a **physical health check** (32%) despite being at greatly increased risk of life-threatening physical conditions. Slightly more carers reported this (42%).

Less than half had been offered **information about the side effects** of medication (47%), even where those side-effects presented significant health risks, such as developing diabetes and rapid weight-gain. Slightly fewer carers reported this (43%).

Just two thirds had been offered involvement in **choices about medication (65%)**. Half of carers reported this (51%).

Only 37% of people had been offered appropriate **involvement of family / friends**, even though this is very important to recovery. Around half of carers reported this (53%).

All of these interventions are well-evidenced and have been found to be effective and cost-effective, yet in order to access the treatment people are meant to get, families are sometimes forced to pay from their own pockets.

Poor access to healthcare

Many people with severe mental illness who were previously eligible for co-ordinated support under the multi-disciplinary Care Programme Approach in secondary care now have much less formal care co-ordination, usually under their GP. GPs and their surgeries are often difficult to access for people with severe mental illness and are not well linked-in with specialist mental health services. In fact, 23% of people with mental illness report experiencing discriminatory treatment from GPs.⁷

Our own survey data shows that GPs often don't feel confident in referring to mental health services. It's clear that mainstream health professionals like GPs need greater support and training to equip them to properly support people with severe mental illness.

Rethink hears time and again of cases where people are in need of professional help, and they, or their families, repeatedly ask for help and get no response. In one case, a family asked 87 times for help, to no avail.

Case study: Mark's story (names have been changed)

Sarah is the mother of Mark, a young man who developed schizophrenia at the age of 19. Following several years of inadequate support and treatment and finally a change in medication, which did not follow prescribing guidelines, Mark took his own life.

“When Mark first became ill, he was referred to an Assertive Outreach team, but only for six weeks. This was not because his health improved. In fact, he became progressively unwell over the next few months until he was sectioned under the Mental Health Act. This was an extremely frightening experience for Mark as he was in a secure adult ward with really disturbed patients. It was pitiful to see his distress and anxiety escalate. Following his discharge from hospital after a 10 week detention, we were left virtually alone. The Community Psychiatric Nurse's visits were irregular and he did not see a psychiatrist again for eight months. Mark was never referred back to the Assertive Outreach team. We do not know why.

In the following year, we arranged for Mark to have help from a Cognitive Behaviour Therapist – and paid for it ourselves. As well as this, we took him to a personal trainer and nutritionist who were all private specialists and paid for by us. Mark really improved during that time, but sadly for one reason or another (one being cost) he decided he did not want to continue. There was no therapeutic help from an NHS psychologist or occupational therapist until two years after his discharge from hospital.

As Mark was fearful to go out in his home town, he asked whether he could see a psychiatrist in the local hospital. We were told that there was no flexibility at all and this was not possible. There was also no emergency helpline available to us because it had been closed down and was only reinstated after Mark's death. His medication was poorly managed and not reviewed thoroughly according to NICE guidelines. Mark was naturally worried about the side effects of long-term antipsychotic drugs, but no health checks were offered by the Mental Health Trust nor instigated by his GP. Nevertheless, he stayed compliant in taking his medication for fear that he may have to be sectioned again.

It is so difficult in the late teens or early twenties for people with mental health problems. Mark became isolated, without any friends at all, nobody to talk to of a similar age, with the exception of his sister who eventually went away to university. This is why it is so important to deal with mental illness as early as possible before the patient's contacts are lost. We firmly believe that had Mark been given the right support and help in the early stages, he would have made a complete recovery and been able to lead a full and productive life.

I would like to add that during Mark's illness we encountered many health professionals who are extremely dedicated and did their best within the limited facilities available to them. I hope that by telling Mark's story, it will give a clearer insight into the problems that people with mental health issues experience within the NHS system and that their needs will be properly addressed.”



Too often the system doesn't 'kick in' until someone has reached a life-threatening crisis point; a crisis that might have been avoided if services had been provided earlier. Often someone living with a condition like schizophrenia or bipolar disorder, and especially their families and carers, know when things are deteriorating and intensive support is needed. But we know that individuals are likely to be told that there is no service for them when they seek voluntary admission to hospital. And there's sometimes no alternative intervention provided in the community.

Good practice and service models do exist – Crisis Resolution and Home Treatment services designed to prevent admission are available, but the picture is mixed across the country, and even where such services exist, they are often under-resourced. In 2007, the National Audit Office reported that the target of 335 teams had been established, but only 50% of people in inpatient care had received an assessment from the Crisis Resolution Team before being hospitalised.⁸

People with Personality Disorders tend to have particular difficulties accessing help. Although the government confirmed that Personality Disorder should not be seen as a 'diagnosis of exclusion' from services, this is still the case for many.⁹

Even those who are fortunate enough to have a professional coordinating their care in the community often find themselves left high and dry when their care coordinator goes on holiday, sick-leave or leaves their job and isn't replaced with someone else.

The impact of this lack of support can also be devastating for carers of people with severe mental illness. A Rethink survey of carers found that 1 in 4 mental health carers provide more than 50 hours per week care, and this combined with emotional stress can have a significant impact on their mental and physical health. 1 in 4 carers also report that they do not have adequate information to help them in their carer role.¹⁰ It is not fair to leave carers who are trying to support a loved one without essential information.

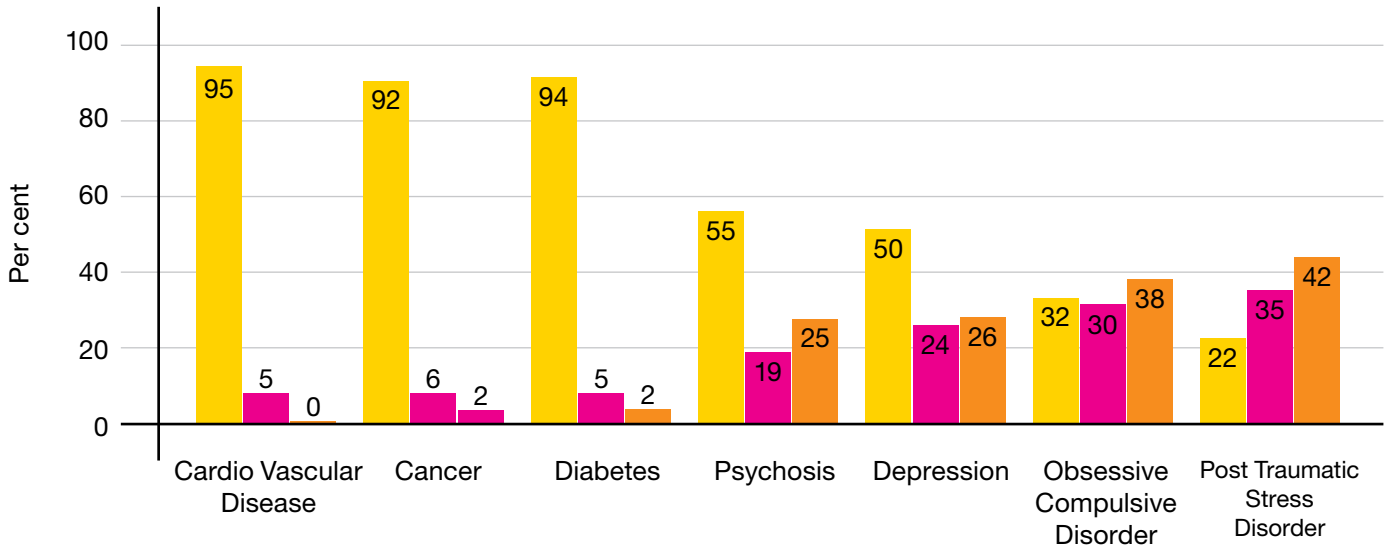
GP survey

251 GPs were interviewed online by ICM Research on behalf of Rethink in June 2010. Interviewees were randomly selected from ICM's nationally representative panel of GPs. Results are broadly representative in terms of age, gender and region. The main findings are:

- Just 50% of GPs are confident in the quality of care that their own relatives would receive from secondary health services for depression – 55% for psychosis, 22% for Post Traumatic Stress Disorder. This compares with 92% of GPs confident in services for cancer, 94% for diabetes and 95% for Cardiovascular Disease.
- When referring a patient with psychosis to secondary care for an assessment, only 1 in 3 GPs are confident in the quality of services available. Only 29% are confident that the patient will be supported to recover long term.
- Only 1% of GPs say they are 'very confident' that a patient with psychosis will not come to harm while awaiting their secondary care assessment.
- Only half of GPs (52%) are confident that a patient with psychosis would receive treatment recommended by NICE.
- When asked whether GPs had the expertise to commission services, 75% said 'Yes' for diabetes, 76% for asthma and 74% for smoking cessation. However, only 31% said 'Yes' for mental health.
- When asked whether they would be able to provide recommended psychological therapy services for psychosis, only 1 in 3 said 'Yes' for Cognitive Behavioural Therapy (CBT) and 1 in 5 said 'Yes' for Family Therapy (34% and 19% respectively).

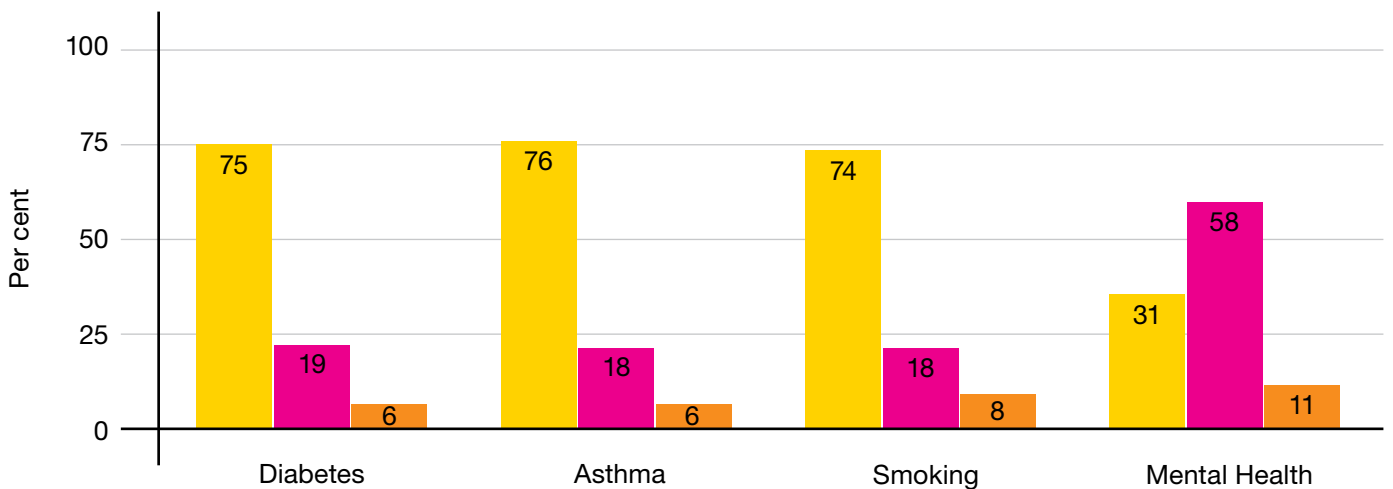
To what extent would you feel confident in the quality of care one of your relatives would receive if they were referred to the appropriate NHS services for each of the following (n=251)

- Confident
- Neither confident nor unconfident
- Not confident



Do you feel you have the right expertise to commission the following services in your area (n=251)

- Yes
- No
- Don't know



Case study: Sheena's story

My son was diagnosed with Bipolar Disorder in 2005. After being 'sectioned' under the Mental Health Act for six months, with medication, he recovered well and relocated to Brighton for a new start. But after being told 'out of the blue' that he didn't have Bipolar Disorder, and not getting good ongoing care, it wasn't long before he was sectioned again. He then started getting into trouble and got caught up in the criminal justice system. He arrived in Scunthorpe in 2009 after been released from prison in Sussex. He was very ill and was admitted into the local mental health hospital. After a week there they decided he had to be transferred back to Brighton as his GP was there. It made no sense as he had nothing to go back to, and no support network.

I followed my son to an intensive care ward where he was held for seven days, and diagnosed with Personality Disorder. I feel he was excluded from mental health services at this point – he was discharged with £50 in his pocket and told to get himself a hostel. But no hostel would take him in.



Instead he was forced to sleep rough on the streets. I discovered this when I received a call from the police asking me to collect him from Doncaster, where he had arrived, alone, and with nothing more than a sleeping bag. It was devastating to know that he'd been abandoned by services in this way, and left in a vulnerable state, homeless and without care.

At this point he was re-admitted to hospital, in Scunthorpe. I understand that this whole trip had cost just under £10,000, yet during this time he never received any medication or treatment. I knew he was very ill and it seemed the services wouldn't offer us help. I couldn't even get through to the crisis team. He was overwhelmed by hearing voices and self-harming, and hit crisis on many occasions. The only support we were able to access was the police. We did this many times and each time we came back to square one – nobody would take seriously our pleas for decent treatment. As next of kin and carer for my son I was incredibly frustrated that nobody listened to me.

Eventually my son was arrested on a public disorder charge and went again through the criminal justice system. I have fought through the courts and finally got him out of the prison and into a medium secure unit where he is finally receiving medication and treatment. I have now been told that my son has indeed got Bipolar Disorder and had become critically ill as he had been left untreated.

Luckily, my son is now in a fabulous hospital, being treated and looked after by dedicated staff. His psychiatrist has indicated that failures in his treatment are what led to my son becoming so unwell. Thankfully he is now making a slow, but good recovery and will now have access to all the mental health services, including psychotherapy. I hope he never again has to suffer what he has gone through the last few years: homelessness, hospital and prison. He is never going to get back the life he's lost, but with love and care, he can rebuild his life.

Psychological therapies

Psychological therapies have been proven to help the recovery of people with severe mental illness within a package of care, including medication, in fact they have been proven to be cost-effective. Cognitive Behavioural Therapy (CBT) is the psychological therapy with the strongest evidence base for severe mental illness, but other forms can be beneficial for people depending on their experiences and preferences.

Accessing psychological therapies is particularly difficult for people with severe mental illness, and many people report that these services are subject

to local cuts. Our survey showed that 41% of all respondents are currently being affected by cuts to health services. Of these, exactly 50% reported that psychological therapies are being affected in their area.

A Rethink member, Angela, explains the importance of psychological therapies like this:

“If you break your leg you go to A & E, have an X-ray, then maybe an operation, then a cast is put on. All that happens relatively quickly, but what would happen if you were told that there was a 12 month waiting list for treatment? You would go home, in pain. There could be circulation problems and nerve damage.



Case study: David's story

“I used to be an Oxford academic and developed schizophrenia during my doctorate. I was a Wellcome Prize

student, one of very few – the future looked promising, but as I worked I became very ill. In 1999, I was admitted to a secure hospital and diagnosed with paranoid schizophrenia. I had lurid auditory and visual hallucinations and unremitting paranoia. I saw, felt and heard things that were extremely distressing.

Over the years I was prescribed a multitude of anti-psychotic drugs, most of which didn't help, but never given psychological therapy. As a last resort I was prescribed the very powerful Clozapine. This did reduce symptoms a little, but it affected my heart – the chest pains were terrifying. The doctor said I'd be dead from heart failure within six months if I didn't stop taking it.

Finally in 2001 I was put on a waiting list for Cognitive Behavioural Therapy (CBT), and was later recommended Dialectical Behaviour

Therapy (DBT), so I was put on the waiting list for that. Two years later I was still waiting. In 2004 I had to move for financial reasons, and I was put on yet another waiting list, again for CBT. I waited nearly five years. In the intervening period my symptoms were overwhelming and I made several attempts to end my own life.

In February last year, 10 years since being diagnosed, I finally started psychological therapy treatment.

I went to the Maudsley Hospital in London every week for sessions of CBT and the therapist helped me to find strategies to cope. I have really bad problems sleeping and CBT has helped with this and really helped with the 'nasty voice'. CBT has helped me remain aloof from this voice and I no longer believe what it says. I now think of the voice as a petty bully and don't let it bother me. It's all about taking back control.

The difference CBT has made is amazing – it has really transformed my life. I am now able to go out and do the things I enjoy. I have learnt strategies that have enabled me to deal with the worst excesses of paranoid schizophrenia. You can change your life by changing your thinking. The only thing I regret is that I didn't have access to it sooner – it could have prevented a lot of suicide attempts and I wouldn't have felt so awful for so long.”

If the joints were involved there could be loss of mobility and if the bones were very displaced they may not heal at all and remain unstable. The pain would increase and there could ultimately be deformity and shortening of the limb.

So what happens to a mind that is broken – a mind that has been so traumatised it has become fragmented. Medication has its place, but so do talking therapies. The person with the broken mind may need another human being who can provide a safe environment and some kind of structure to enable them to untangle those thoughts, to release anger and shed tears, to free up those channels in the mind that have become blocked. If left too long, the person with the broken mind may do whatever they can to survive, however maladaptive their strategies may seem. There may come a time when all that is inside can no longer be contained and the result is like a pressure cooker exploding, with disastrous results.

The issues of waiting lists must be addressed. Tightening up the eligibility criteria for certain treatments is not the answer. I once heard a consultant clinical psychologist report that there had only been two suicides on the waiting list that year. Only two?!”

The Improving Access to Psychological Therapies (IAPT) programme has undoubtedly been a great success, and the government’s commitment to psychological therapies is very welcome – but it currently only offers treatment for mild to moderate depression and anxiety, rather than treatment for more severe conditions. The 1.5 million people with severe mental illness also need to get the benefit.

In 2009, the Mental Health Act Commission said of access to psychological therapies in inpatient settings:

“We recognise that the government wishes to increase access to psychological therapies, although there may be a danger that such increased access focuses too exclusively on community-based services and primary care, so that detention in hospital actually becomes a bar to access.”¹¹

Rethink frequently hears from people who have been unable to access psychological therapies. This may be because following referral, the wait is excessively long, with therapy only becoming available after several months, when the person could have become too ill to benefit from it; in other cases it isn’t offered at all.

Inpatient care

Inpatient care is an important part of the full care package, especially when planned. While we recognise that alternatives to inpatient care can reduce reliance on admission, it is essential that enough inpatient care is provided in each area, both to provide for emergency admissions, and crucially, for planned, voluntary admission, to avert a life-threatening mental health crisis. Unfortunately, the figures suggest that ‘planned’ admissions like this are not the norm; in 2009, 31.8 per cent of people who spent time as an inpatient were compulsorily detained in hospital under the Mental Health Act.¹² This is a larger percentage of all inpatients than in previous years and the data shows a steady increase in the percentage of inpatients that are detained.

The Mental Health Act Commission found that from 2007-2009, 30% of acute mental health wards were over-occupied, and 27% were running at full occupancy.¹³ Over-occupied wards are not the safe havens that they should be for in-patients. In 2009, the Care Quality Commission found that, of people who had recently been discharged from inpatient mental health care, 16% of inpatients never felt safe, with 39% reporting that they felt safe only some of the time.¹⁴ The most recent *Count Me In* census of mental health patient gives us clues as to why. In 2009, 67% of respondents were not in a single-sex ward – similar proportions as in 2007 and 2008, while 1 in 5 men and a quarter of women did not have access to toilet or bathing facilities designated for single-sex use.¹⁵

Other research shows that higher than recommended dose levels and combinations of antipsychotic medications (against prescribing guidelines) are common on adult wards.¹⁶ Finally, nearly half (48%) of mental health inpatients said they did not receive information about the possible side-effects of medication in a way they could understand.¹⁷

Deaths in inpatient care

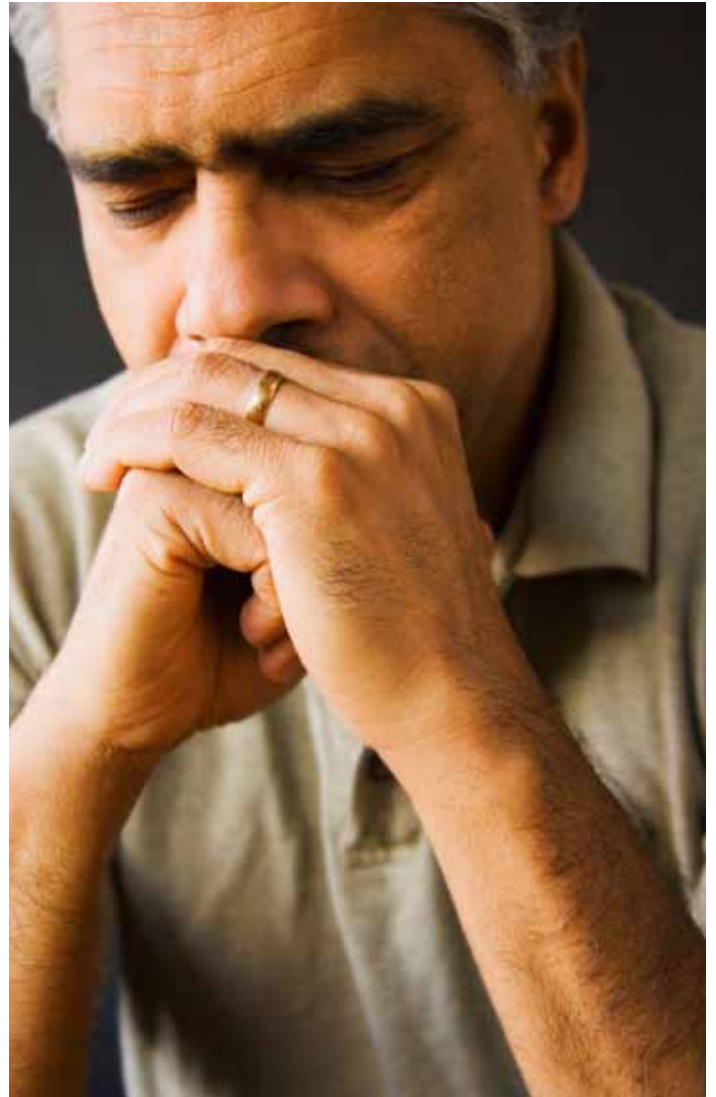
The final Mental Health Act Commission biennial report 2008 highlights the deaths of patients who are detained under the Mental Health Act.

“Mental health patients can be vulnerable to cardiac or respiratory arrest through coexisting physical illness, self-harm, and the effects of medication, including rapid tranquilisation. Our data suggests that approximately one in five ‘natural causes’ deaths involving detained patients noted between 2005 and 2008 can be directly attributed to such causes.

It is possible, of course, that some of these deaths have at least an iatrogenic element, in that medication or other treatment causes or exacerbates physical decline, and as such are questionably of ‘natural causes’ at all.”

Currently, only deaths due to ‘unnatural’ causes are subject to an inquest investigation. However, systemic failures can lead to death by supposedly ‘natural causes’ linked to treatment or indeed neglect. Recent attempts were made to change the law on reporting deaths, so that deaths by ‘natural causes’ would be reported to the Coroner, in case further investigation may uncover contributing factors. This change was not carried into the updated Coroners and Justice Act 2009, and these deaths still go uninvestigated. So, while all deaths in police custody or prison are reported, many deaths in psychiatric care which may be due to unnatural causes are not.

Rethink has advised families in cases where a Mental Health Act ‘section’ has been lifted when a person is dying, so that there is no need to report the death to the Coroner for investigation. The solution to this would be extending the requirement to report deaths to apply to those who have recently been detained under the Mental Health Act. It is not fair to leave these deaths uninvestigated.



Criminal justice

In the absence of decent mental health crisis services, it’s often the police who are left dealing with individuals in distress. The symptoms of severe mental illness can, if not addressed with appropriate health service interventions, lead to criminal behaviour (generally non-violent). The police are often ill-equipped to assess and appropriately deal with a person with a condition like schizophrenia, personality disorder or bipolar disorder, but where health services aren’t there to respond, they have little choice.

A person with a severe mental illness may lose access to essential medication and their mental and physical health are likely to go unchecked throughout the criminal justice process, and especially in prisons, where there’s often inadequate healthcare for people with a mental illness. It is not fair to leave people without treatment they need.

Physical health and mortality

It is not just the provision of mental healthcare that is unfair – people with severe mental illness do not get the physical healthcare that the rest of the population takes for granted. In 2006, a Disability Rights Commission investigation found that people with long term mental health problems die on average 5-10 years younger than other citizens, often from preventable physical illnesses (rather than suicide).¹⁸

A wide-ranging review, informing this report, found that:

- people with severe mental illness are twice as likely to die early than the general population
- deaths from 'natural causes', i.e. not suicide or sudden death, accounted for 62% of the premature deaths
- 10% of people with schizophrenia will die by suicide
- people with schizophrenia are almost three times more likely to develop diabetes than the general population
- people with schizophrenia are 90% more likely to develop bowel cancer, and women with schizophrenia are 42% more likely to develop breast cancer
- the risk of death for people with coronary heart disease, diabetes, stroke and chronic obstructive pulmonary disease is 43%-77% higher for people with schizophrenia than those without
- people with schizophrenia or bipolar disorder are 1.6 times more likely to develop ischaemic heart disease, 1.9 times more likely to have a stroke, and 1.3 times more likely to have hypertension ¹⁹

Annual physical health checks are essential for people with severe mental illness. Support to live healthily, and to manage the side effects of antipsychotic medications, would go a long way towards reducing the high mortality rates that exist for people with severe mental illnesses like schizophrenia.

Case study: Yvonne's story



My name is Yvonne Stewart-Williams. I am a 48 year old black single parent, living in South London. I was diagnosed with Schizo-affective disorder, which is a mixture of bipolar and schizophrenia, in 1993. I was prescribed anti-psychotic medication daily and I was supported by a Care Coordinator, psychiatrist and in group psychotherapy. I ceased the psychotherapy after three years, as I was well and had gained full time employment.

In 2009 my medication was reduced gradually and I became unwell again. I had delusional beliefs about someone – sending them gifts, text messages and flowers. I was never violent, but I was very unwell. I would have benefited at this stage from a short stay (perhaps three weeks) in a community respite home. I wasn't ill enough to be admitted to hospital, but I was unwell enough to be behaving in a way that meant I got caught up in the criminal justice system. In the end I was charged with harassment and sentenced to a prison stay. I think this could have been avoided.

I was in prison for eight weeks, and while there, I received my medication inconsistently and at varying doses. This meant that my mental health got progressively worse and I started to believe that my delusions were real. I was informed of a new diagnosis while on my own in a holding court cell prior to my final hearing when reading my psychiatric report. It wasn't explained to me and I wasn't offered any support. At my final hearing the judge said I was to go for treatment at the Maudsley Psychiatric Hospital. But I remained in prison for several weeks until this took place.

I was in prison for a total of eight weeks and the effect of this on me was traumatic. I went on to spend a further three months in a psychiatric hospital, longer than I'd ever stayed before. This was devastating for me and my ten-year-old son, who was taken into care for nine months, and having a criminal record has meant I have had to change my job.

The GP contract now has an indicator requiring GPs to invite people with severe mental illness to be registered to receive these annual health checks. However, recent inquiries suggest that there is great variation in the adherence to this indicator. Our survey found that fewer than half of respondents were informed about potential side effects and less than one third were offered annual physical health checks.

One reason for the disparity between GP reports and patient experience is that the Severe Mental Illness register works differently from all of the other disease registers in primary care. It is the only register that requires patient consent to be included. There are significant data sharing issues in mental health, due to stigma and prejudice. However, primary care disease registers are not made public – they do not contain any ‘new’ sensitive data about patients, they are simply a way to aggregate records according to disease categories. At the moment, Quality and Outcomes Framework (QOF) payments are rewarding GPs for merely contacting people with severe mental illness to ask for consent to be on the register. It is not fair to reward health professionals when patients are not getting results.



Missed opportunities

Ten years ago, the government announced that the three priorities of the NHS would be cardiovascular disease, cancer and mental health. The commitment to mental health was laudable and necessary, and the National Service Framework created an entirely new approach to mental health, with different treatment models for Early Intervention, Assertive Outreach and crisis care, alongside commitments to support for carers.

Since then, however, people with severe mental illness have been explicitly excluded from major NHS initiatives such as Choice, Payment by Results and Improving Access to Psychological Therapies (IAPT) – even the mental health acute inpatient survey was not taken seriously.

Choice

Mental health has been completely excluded from the Choice agenda. The NHS Constitution promises that all patients will have the right to choose where they receive treatment – it fails to mention that patients with severe mental illness, along with pregnant women, currently have no such right. Choose and Book has opened up a much more flexible system for people in need of physical health treatment, but people using secondary mental health services cannot choose different providers, even where the relationship with a provider might have broken down, or care is offered in a location miles away from family, friends and a support network. It is not fair to deny people with severe mental illness the choices that other NHS users take for granted.

Payment by results

The ‘Payment By Results’ (PbR) initiative sets out a national tariff of costs per patient (in categories) and is designed to improve efficiency. This hasn’t yet been applied to mental health services. While non-mental health trusts use a national tariff, mental health trusts do not. The independent regulator Monitor, and the NHS Confederation both acknowledge that this lack of transparency leaves mental health services more susceptible to cuts. In

the past, this has led to millions of pounds worth of cuts in mental health trusts, which find themselves having to bail out acute trusts even where their own budgets are in order.²⁰

We recognise that PbR for mental health is now under development, with 'patient cluster' classifications now available for use by trusts to develop local tariffs. However, the earliest possible date for a national tariff is 2013/14, a full ten years after the introduction of PbR to non-mental health acute trusts. This delay has left mental health services more vulnerable to cuts, as cutting block contracts is far less risky than cutting spending under PbR, leaving people with severe mental illness with worse health outcomes. It is not fair to leave mental health services shouldering more than its share of the burden when budgets are tightened.

Mental health acute inpatient survey

The introduction of the Mental Health Acute Inpatient Service Users' Survey was a welcome opportunity to measure the experience of people with mental illness. In 2009, the Care Quality Commission surveyed over 7,500 people. It found that less than half of patients in mental health services "always" felt safe in hospital.

It should have been a catalyst for action, so it was very disappointing when the relevant minister dismissed the results because some of the people surveyed were being treated under section. The implication was that mental health in-patient concerns over safety couldn't be taken seriously.



Case study: Bill's story

My name's Bill. I've had severe depression and Obsessive Compulsive Disorder for several years. I've also developed physical health

problems with my bowel. Unfortunately I didn't establish a good trusting relationship with the psychiatrist at my local hospital and lost confidence in the treatment I received there. So, wanting to do all I could to recover, I asked to move to a different mental health team. I was denied this – and told that the right to choose where treatment is received didn't apply to mental health.

When I was referred to a specialist for a bowel complaint, my experience couldn't have been more different. I was given the option to choose my care provider through the 'Choose and Book' system. I was offered a choice of several providers and was encouraged to choose the right one for me. There was no pressure to be treated

at my local hospital and I actually chose one quite far from home. It seemed unfair to me that I had the right to choice concerning my physical health needs, but not my mental health needs.

I was told I'd have to take the matter up with the mental health trust. This is challenging at the best of times, but especially so for someone experiencing severe depression. To make matters worse, the head of the trust was the very same psychiatrist from whose care I wanted to be removed. I seemed to be trapped in a vicious circle and have no choices or control over my care. I went through the entire health complaint process, which went right through to the Health Ombudsman. Their response was simply that there is no choice in mental health.

In the end, I sought advice from a solicitor, and lo and behold, I was allowed to change mental healthcare provider. I got what I needed in the end, but I lost out on a few years' psychiatric treatment and psychotherapy because no alternative service was offered to me. I had to involve community care legal advice, my MP and MEP, civil servants, Citizens Advice, advocacy services and journalists to access a different mental health service. It shouldn't have been such a difficult battle and I know for many it's one they'd be unable to fight.

While some individuals' symptoms may contribute to feeling unsafe, that doesn't tell the whole story. The proportion of people reporting a lack of safety was so high as to be compelling, and families and carers outside of hospitals reported similar concerns.

Whether people are being treated as voluntary patients or under compulsion, everyone using NHS services should feel safe – indeed a feeling of safety is a pre-requisite for a therapeutic environment.²¹ It is impossible to achieve good health outcomes in inpatient care without a therapeutic environment. That means everyone feeling safe, no matter what their condition.

Other initiatives

The National Service Framework (NSF) undoubtedly led to real improvements in mental health service provision, though it did not meet its target for carer support.²² When it expired this year, it was replaced with a new plan – New Horizons – a vision for mental health for the next 10 years.²³ This was intended to be the previous government's flagship mental health strategy for England, but unlike health initiatives for physical health, it wasn't backed by any funding and contained no delivery plan or outcomes to be achieved, either for service-users or their carers.

The five-year DRE (Delivering Race Equality) strategy was launched in 2005.²⁴ Key objectives included a reduction in the numbers of black patients sectioned under the Mental Health Act, improved access to psychological therapies for black patients, and a reduction in the numbers of black patients that are restrained and placed in seclusion.

So far little has been achieved – the most recent and final *Count Me In* census found that the number of black people detained under the Mental Health Act is three times the average for all patients, and that there is 'no sign of decline in admission rates of black and minority ethnic groups'.



Improving Access to Psychological Therapy (IAPT)

The national commitment made to improving access to psychological therapies was undoubtedly positive for mental health. We appreciate that the intention was that dedicated services for mild and moderate conditions would free up waiting lists for psychological therapies for people with severe mental illness. However, over half of people with schizophrenia and bipolar disorder are not offered psychological therapy (51%).

People with mild to moderate depression and anxiety have received great benefits from being able to access talking therapies. That benefit now needs to be felt by people with severe mental illnesses too and resources fairly distributed.

It's time to act now

Over 12,000 people signed a Rethink petition in the run-up to the General Election: the message was simple – ‘I care about mental illness and I want a government that cares too’. The thousands of signatories were joined in support by celebrities such as Stephen Fry, Ruby Wax, Jo Brand, Arthur Smith and Martin Freeman, and 15% of the new Parliament pledged to champion mental health during this session.

There's no doubt that mental health is a defining issue of our times, and it touches most of us. 56% of people say that someone close to them (a family member, close friend, or themselves) has experienced a mental illness.²⁵ A lot of people care.

We also know that need is greater than ever. In a time of economic hardship, when people are losing jobs and often struggling to maintain a home, the demand for mental health services is likely to be greater than ever. International evidence suggests that economic crises lead to increased demand for mental health services.^{26,27}

Every day, Rethink comes into direct contact with people with mental illness and carers who tell us that financial pressures have triggered episodes of illness. This is not merely a question of credit crunch blues. Vulnerable people who have not previously had to deal with serious financial difficulties may find it overwhelmingly hard to cope without appropriate specialist support.



John Bercow, Speaker of the House, pledges his support



Rethink expects that different elements of the current economic crisis – home repossession, debt and unemployment – will all take their toll. Stressful life events can not only trigger mental illness, but cause relapses and exacerbations of existing conditions. Now, more than ever, people who are most in need, and most vulnerable, need the government's protection.

Rethink is encouraged that the coalition government's programme for government includes a firm promise to ensure that fairness, and protection of those in need is at the heart of any difficult decisions about public expenditure. Along with thousands of supporters, Rethink is calling on the government to spend wisely, on mental health services that are both effective and cost effective. There's a real opportunity right at this moment to deliver fair treatment now.

It doesn't have to be this way – real solutions

The new government's health policies can help to make treatment fair. The Secretary of State for Health has committed to monitoring outcomes rather than process targets, encouraging shared decision-making, creating a new model for collective engagement and increasing access to psychological therapies. Each of these initiatives has the potential to give at least a million and a half people the fair treatment they deserve.

Outcomes

The real aim of mental health treatment is to prevent death and to support recovery. The following outcome measures would support these aims:

1. Stigma and discrimination are still major barriers to recovery. The new government's focus on public health is welcome. For people with severe mental illness to recover and for people with early symptoms to get help early, attitudes to severe mental illness need to change. **Public attitudes to mental illness** are already monitored annually and should form one of the new outcomes by which we judge the new NHS.

2. To stop people with severe mental illness dying from preventable physical conditions, we should hold providers accountable for reducing **difference in mortality rates between people with schizophrenia and bipolar disorder and the general population.** This gap needs to be closed to ensure that people receive essential healthcare for conditions such as cancer, diabetes and CVD deaths.

3. Over 1000 people receiving mental healthcare die by suicide and sudden unexplained deaths each year.²⁸ According to WHO, suicide is still the leading cause of death in people with schizophrenia.²⁹ Services should be judged by their ability to reduce the rate of suicide, attempted suicide and sudden unexplained deaths in inpatient care.

4. Mental health services aim to help people recover a good quality of life. Mental illness has an impact beyond the symptoms of the illness, including on employment, social networks and ability to perform basic life skills. Ensuring that people are able to function in these areas is part of ensuring 'survival'.

The **recovery star** is an evidence-based measure, which measures the impact of services and interventions on people's self-care and living skills, ability to participate in employment, social networks and relationships, management of symptoms, self-esteem, trust and hope. Rethink has used this tool to measure the impact of interventions with young people. **All interventions should be judged on outcomes on the recovery star.**

5. A pre-requisite of good crisis care is that people feel safe. As a proxy for a true outcome measure, **patient and carer-reported outcome measures in both inpatient and alternative crisis settings** should be captured to ensure that patient experience is comparable in safety, quality and cleanliness to physical health settings. Carers and family members offer a valuable perspective on the quality of services, especially in crisis care when a patient's mental capacity may be impaired for short periods of time.

6. The longer a person experiences psychotic symptoms but does not receive treatment, the more difficult it is to provide effective treatment as symptoms worsen during the wait for treatment. Well-established methods exist to **measure the duration of untreated psychosis.** Measuring this outcome would ensure that services intervened early rather than waiting for a crisis to occur before providing treatment, which is unnecessarily lengthy, intrusive and costly.

7. The proportion of inpatients being treated under compulsory powers for mental illness is increasing – rising from 23.7% in 2004-5, to 31.8% in 2008-9.³⁰ The number of people being treated under community treatment orders is approximately six times the estimate given when the Mental Health Act was passed.³¹

While there will always be a need for compulsory treatment in some cases, a system which relies on compulsory treatment is failing to treat people early, when treatment can be more effective, better value for money and less disruptive to family life and identity. Commissioners should be providing services that **reduce the level of compulsory treatment**, not add to it.

8. Only 3% of people with schizophrenia and bipolar disorder being treated under the Care Programme Approach are in employment.³² While not everyone with a severe mental illness will be able to sustain paid employment, a higher employment rate would be a sign of increased community participation and could be considered a proxy outcome for social functioning. However, many people with schizophrenia and bipolar disorder will benefit from working part-time, making it essential that part-time work is considered as valid an outcome as full-time employment.

Employment rates should also be tracked according to disability or impairment, though we caution that longitudinal tracking of *sustained* employment is more meaningful than taking a 'snapshot' impression at any given time. An increase in sustained employment would demonstrate effective employment support for people with severe mental illness.

9. 1 in 4 carers also report that they do not have adequate information to help them in their carer role.³³ The National Institute for Health and Clinical Excellence recommends that carers are appropriately supported, and provided with the information they need. A measure should be introduced which identifies the extent to which carers feel informed.

10. To ensure mental health services work towards these outcomes, Payment by Results should be extended to the mental health sector as soon as possible. The plan to incentivise health providers to reduce emergency re-admissions should include mental health trusts.

Shared decision-making

A key part of the new direction for the NHS is an increase in accessibility and availability of information for patients and a new power balance between patients and health professionals. People receiving treatment from mental health services are currently denied information about key issues, such as side effects of medication: 48% of patients say that potential side effects of medicines that they were prescribed while in hospital were not explained to them in a way they could understand. 29% were not given information on how they could get help in a crisis after they were discharged.³⁴

A **patient and carer reported outcome measure regarding information provision** would ensure that services prioritise giving information as well as more traditional aspects of healthcare provision. Carers and family members may need to request help in a crisis rather than the unwell person, which makes it essential for them also to have basic information about how to seek help in a crisis as well as how to support their relative in the longer term.

23% of people with mental illness report GPs discriminating against them and 19% report discrimination by psychiatrists.³⁵ Discriminatory attitudes preclude shared decision-making and must be challenged to allow this new model to operate in mental health services. Social marketing techniques need to be applied to health professionals to change attitudes and behaviour as much as to patients, including programmes such as Rethink's Education Not Discrimination (END) programme.

END has been evaluated by the Institute of Psychiatry. The programme is on-going but emerging findings indicate positive changes in participant knowledge, attitudes, intended behaviour and empathy levels. Previous research from the Rethink – Institute of Psychiatry anti-stigma training and evaluation collaboration with medical schools also shows positive knowledge changes using an information and personal testimony educative model.

Planning ahead

Emergency readmissions may reduce long-term cognitive and social function. As with other health services, **emergency re-admission rates** over 30 and 90 days should be collated for mental health services. If other health services are to be penalised for emergency readmissions, this should apply to mental health services too. Acute mental health services must be held more accountable for ensuring that intervention has been effective.

Collective engagement

Proposals for a new body, HealthWatch, to replace LINks at local level, with a national presence, could end up excluding people with severe mental illness. Patient and Public Involvement (PPI) programmes have not tended to be accessible to the most stigmatised and vulnerable patients, including people with severe mental illness, as participants tend to replicate the stigmatising attitudes of other members of the British public. At a national level,



Case study:

Lynn

My son has treatment-resistant paranoid schizophrenia for which he takes the anti-psychotic drug, clozapine. The drug has greatly improved his mental state but,

unfortunately, it has many side effects – one of which is to trigger Type 1 diabetes. In March 2003 my son became diabetic and, due to the lack of adequate physical health checks in the clozapine clinic, his medical team failed to identify this.

I made a formal complaint to the Hertfordshire Partnership NHS Trust regarding my son's poor standard of care but, 18 months later, the situation had not been resolved, the Trust had concluded its investigations and closed the file.

In January 2005 I wrote to the Healthcare Commission and, a further 18 months later in July 2006, the Commission found in my favour on 12 of the 13 issues which comprised my complaint. Despite assurances from the Trust, I investigated and proved that they had failed to implement many of the recommendations made by the Commission. By that time I had spent a disproportionate amount of time trying to obtain satisfactory answers to my questions and had met with ambiguity, contradiction, failure to provide me with relevant information, medical

and management incompetence – and verbal abuse. I also learned that there was no legal requirement to implement the Commission's recommendations – which made a mockery of the complaints procedure.

I raised this issue at Rethink's AGM in 2007, and the Campaigns Team used my story in their discussions on proposed amendments to the new Health and Social Care Bill. As a result, the Bill was amended, specifying that the new CQC's regulations should: 'make provision as to the handling of complaints and disputes and the application of lessons learnt from them'.

In the meantime, I wrote again to the Healthcare Commission and in April 2008 they upheld my further complaint over lack of compliance with their recommendations.

June 2010 – 7 years later and the present situation is that most of the Commission's recommendations have been implemented – but not without a struggle, and constant monitoring is a necessity. The Trust is updating its clozapine protocol documentation, and is also reviewing its clozapine clinic and CPA procedures. Most importantly and satisfyingly for me, it has finally set up a Physical Health Checks Steering Committee, of which I am a member. Needless to say, Rethink's Physical Health Check Tool has played a considerable part in our discussions.

Little did I think when I started my complaint that it would take such a long time for the procedures to be corrected, and I can only hope that at least some of my endeavours will help to improve the physical well being of my son and others like him.

HealthWatch should focus strategically on health conditions that are stigmatised and may be on the margins of debate at local level. Local arms of HealthWatch would be well placed to monitor local complaint processes and outcomes.

Increasing access to psychological therapies

The coalition programme promises to 'ensure greater access to talking therapies to reduce long-term costs for the NHS'. The Secretary of State has guaranteed the roll-out of IAPT sites, which provide treatment for mild to moderate depression and anxiety. This is a positive move, which will help to make psychological therapies part of mainstream NHS provision. However, the sites do not currently provide interventions suitable for symptoms of severe mental illnesses such as schizophrenia, bipolar disorder, personality disorders and severe depression, despite NICE recommending these treatments and finding them to be both effective and cost-effective. In no other healthcare area would we restrict treatments to people with less severe conditions. Plans to increase access to psychological therapies must begin to include interventions for severe mental illness.



Personalisation

Personalisation in health and social care has the potential to offer real choice and control for people with severe mental illness. It is essential that appropriate support is provided to people to identify their recovery goals and to access the right support. Personalisation will only provide fair treatment if health and social care budgets are joined up. Rethink is currently involved in the pilot of Personal Budgets for healthcare in Doncaster, and we will share the results of our work later this year.

GP commissioning

Where mainstream health professionals are granted greater freedoms to make decisions about service provision, it is essential that they are equipped to engage with the most vulnerable in society. Our survey of GPs found worrying results: while around 75% of GPs feel they have the expertise to commission services for asthma, diabetes and smoking cessation, fewer than 1 in 3 can say the same about commissioning for mental health.

Before GP commissioning is implemented, consideration must be given to whether GPs are best-placed to commission services for groups like people with severe mental illness, who are a minority on any GP list and who often do not engage with, or trust, primary care professionals. The new independent health board may be better placed to commission for groups which are minorities in any locality, but who make up over a million and a half people nationally. In any event, if mainstream or non-specialist health professionals are to commission mental health services they will require proper training and support in understanding the needs of people with severe mental illnesses like schizophrenia.

Funding allocations must be appropriate to incentivise GPs to commission for this group. GPs may be able to commission services for a broader range of people with mild to moderate depression and anxiety, as long as there is at least one GP with a special interest in mental health in each GP cluster.

Can we afford fair treatment?

Fair treatment need not cost more – in fact overall it costs less in the medium to long-term. Treatments and services do exist that provide fair treatment in a cost-effective manner. Public services should always seek to ensure that interventions are cost-effective, but particularly in a time of economic austerity. When it comes to fair treatment in mental health services, we can't afford *not* to act.

Psychological therapies

A recent review of efficacy and cost-effectiveness of psychological therapies found that Cognitive Behavioural Therapy (CBT) was most effective for people with schizophrenia, whereas CBT and other psychological therapies are effective for people with depression and bipolar disorder. Non-CBT approaches are recommended for Personality Disorders. CBT was found to reduce rates of hospitalisation as part of a package of care; as well as length of hospital stay, symptom severity, and weight gain resulting from antipsychotic medication.

Case study: Paul (not real name)

Paul is a 57-year-old man who was 'sectioned' under the Mental Health Act when he was 51. He reported more than 20 years of surveillance and persecution by the Mafia. These beliefs began during an episode of delusional thinking within months of him losing his job as an accountant.

He had been feeling increasingly uneasy (delusional mood) and then saw a procession of black cars. He developed the delusion that the Mafia were following him and watching him. At the time of admission he said that he had suffered enough, he had been intending to travel to London to drown himself in the Thames.

Paul had very little insight into his symptoms and believed that taking medication would sedate him and leave him more at risk from the Mafia. Cognitive Behavioural Therapy on the inpatient unit was provided to explore the onset and meaning of the delusions once anxiety had been reduced and Paul felt safe to talk. Initially he was taught to tackle his anxious thoughts using rational responses and relaxation. He was then able to identify some coping strategies from a list of coping skills available on the ward.

With trust now increasing and anxiety reducing, a timeline was developed to try to understand the

roots of the delusion. This revealed that there had been Italian prisoners of war held near the family farm at one point and he had come to believe that perhaps his real father was a prisoner of war and a member of the Mafia. Family photographs were brought out and as he began to understand his past better he realised that some of the comments made may have been taken too personally and out of context and also that the chronology didn't fit.

He had started to become really depressed about his childhood, the loss of his job and because of his delusion. CBT focussed on working on his underlying belief that he was different and a failure and he started to chart the successes in his life. He came to accept that his was a normal childhood and he hadn't been neglected by family and his mood improved.

At this point he was much more energetic and active and began to develop a plan to return to part-time work. Paul was never keen on antipsychotic medication, but did agree to take a low dose each day to prevent relapse. In this case medication alone could not have delivered the degree of recovery achieved with CBT and in the end led to good adherence with low dose antipsychotics.

Offering CBT to people with schizophrenia in addition to standard care yielded net savings of just under £1000 per person. This analysis only included direct service costs for schizophrenia in estimating savings, and therefore does not include further savings to health and social care or through increased productivity of the person.³⁶

The review concludes that: “The systematic review of economic evidence showed that provision of CBT to people with schizophrenia in the UK improved clinical outcomes at no additional cost.” It is fairer on people with severe mental illness, and fairer to the taxpayer, to take these findings seriously, and recognise the benefits and cost-effectiveness of psychological therapies for severe mental illness.

Early Intervention in Psychosis teams (EIIP)

In 2008, the King’s Fund found that immediate savings of up to £9 million could be made if early intervention services were provided to 60 per cent of new cases of schizophrenia. This could increase to £44 million if coverage were 100 per cent.³⁷ An evaluation of an early detection service for people with early signs of psychosis found that in the second year of EIIP provision, costs per person receiving the service were £960 lower than those not receiving it, due to reduced lost work and reduced admission to inpatient care.³⁸

For those experiencing fully developed psychosis, a costing model for Early Intervention Services found that savings of just under £5000 per person were made over a year due to lower rates of admission and re-admission.³⁹

For people from Black and Minority Ethnic groups, savings of over 30% of the costs of usual care have been estimated. In fact, this is thought to be an underestimate of savings as a number of cost impacts have not been included in studies thus far.⁴⁰

Crisis Resolution and Home Treatment Teams (CRHT)

Crisis Resolution and Home Treatment Teams have been shown to yield savings. Over six months, the costs per person have been found to be just under £2200 lower for those with access to CRHT than those without.⁴¹

Case study: Beth



In 2006 I became unwell while finishing my English degree. My world fell apart and I was sectioned for a month under the Mental Health Act; my experience of inpatient care was dehumanising and at times, deeply frightening. By the time I was discharged, I was no longer manic, but had entered a deep depression which lasted for six months.

I was referred to my local Early Intervention In Psychosis team (EIIP), and was allocated a Community Psychiatric Nurse (CPN), who was also my care co-ordinator. Over the next three years, I developed a great trust and respect for my CPN and the team. I accessed several courses of CBT to help me understand my experience of psychosis and rebuild my life.

When I became unwell again in 2008, my CPN and my psychiatrist were there to catch me early, and instead of returning to the inpatient setting I found so traumatic, I was able to spend ten days in a crisis house. The crisis house was a refuge, allowing me to leave behind the stresses of work and home life, and focus on my own recovery.

In February 2009 my CPN referred me for art therapy; this provided me with a way to express some of the deeply distressing emotions raised by my disorder. It also provided me with a safe environment to meet people who suffer in a similar way and make life-long friends. My CPN also helped me to apply for funding to attend a ceramics course; I find working with clay deeply soothing and therapeutic. Discovering a creative outlet has really brought my recovery along in leaps and bounds.

In December 2009, when I became ill for a third time, the EIIP consultant diagnosed me with Bipolar Disorder. This was a turning point in my recovery, as it led to the correct drugs, which have allowed me to return almost to my healthy self.

I have now reached the end of my time with the EIIP team, and I’m certain, without the support of my CPN and the team, I would not now be in full time work and enjoying my life again.

Subsequent research provided further evidence to suggest that Crisis Resolution Teams save money with six-month cost savings of as much as £2438 per person.⁴²

With regards to alternatives to inpatient hospital care, there is evidence that residential alternatives to inpatient wards may be cheaper and more acceptable to some patients. Further research on the clinical effectiveness of standard wards versus residential alternatives is needed.⁴³ One major element of the importance of effective crisis care is the impact on carers. When no help is available, it falls to families and carers to cope with often extremely distressing and chaotic situations.

Criminal justice

Prison places are an expensive alternative to good mental healthcare. A criminal justice system which identified people with severe mental illness early would be able to reduce prison places.

Diversion schemes are the interface between the criminal justice and mental health systems. They aim to identify people for whom mental health care is more appropriate than imprisonment. Diversion schemes are proven to be effective and cost-efficient. A recent pilot based on a service-level agreement between the courts and local NHS mental health trust demonstrated a reduction of 55% of formal psychiatric reports needed and a reduction of over 70% in the amount of time taken for mental health advice to be provided to the courts. This amounted to the equivalent of 39 days, which implies a potential saving of around £4200 per case for those held in remand.⁴⁴

The diversion of an offender with mental health problems towards effective community treatment is estimated to result in savings of over £20,000, due to likely reductions in future spending.⁴⁵ Fair treatment would mean saved lives and saved money – contributing towards the significant savings planned for the Ministry of Justice.

Inpatient care

Inpatient care is undoubtedly expensive, especially secure care. Hospitalisation represents very poor value for money compared with alternative crisis care, and is a distressing experience for the patient

and caring family alike. Preventing hospitalisation also leads to financial savings, with potential for more than £2000 per person per year to be saved.⁴⁶ Furthermore, there's evidence that in severe mental illnesses, repeated crisis episodes like this can have a long-term negative impact on rates of recovery and do real damage to overall health. The tragedy of this situation is that many such crises, hospital admissions (and re-admissions) could have been prevented.

Where a good reliable network of other healthcare exists, mental health services could become less reliant on inpatient care. When early intervention teams provide support early, community mental health teams work with people long-term towards recovery and alternative crisis accommodation is available, rates of admission could be reduced. This could result in reduced spending on inpatient care and the administrative cost of compulsory treatment. In areas where wards are over-occupied, carers are over-burdened and community services lacking, there is no choice but to continue with this expensive option. A good mental health system could have fewer inpatient services, but not at the expense of good health outcomes for both people with severe mental illness and their families.

Individual Placement Support (Employment)

Individual Placement Support (IPS) is an employment support approach based on several principles, such as locating employment specialists and clinical mental health teams together. It is a proven model, and is recommended by NICE for people with schizophrenia.

The cost effectiveness of this approach is well evidenced. The employment rate for IPS programmes has been found to be 61%, compared with 23% for traditional employment schemes. Research has shown that mental health inpatient costs over an 18-month period see a saving of £6,000 per client, which is double the cost of providing the IPS service to them.⁴⁷

Mental health spending for those who found work has been found to fall by 60% over 12 months for those accessing IPS. Over 10 years, service costs for those in work through IPS is 50% lower – this represents a saving of £50,000 over ten years for a person with schizophrenia.⁴⁸

Case study: Louise's story

My name is Louise and I've been a Mental Health Service user for the last nine years. I entered a hospital setting after taking an overdose. I'd been struggling with depression for years, throughout school and work, but couldn't bring myself to do anything about it. The duty psychiatrist in A&E said that he wanted me to go to an open unit for a couple of days, just until I was safe to be on my own. In fact I didn't get out again until eight years later, last year.

I deteriorated in hospital. There was no facility for therapy, no activities to pass the time and no other unit could be persuaded to take me as I became more and more angry, began to self-harm, abscond, fight, and eventually assaulted another patient.

This time I was accepted by Broadmoor and more than anything else that felt like the end. Several months later the police paid me a visit to charge me with the assault. Luckily I had a fantastic nurse who explained my rights to seek legal representation. My solicitor knew all the procedures, the options available, the likely course of care pathways. So when it came to being sentenced the recommendation for a hospital order had already been made and I returned to Broadmoor without disruption.

A hospital order is by no means an easy option. The emphasis is on treatment and often lasts longer than a prison sentence would do on its own. Yet in stark contrast to what could ever be provided in prison I had access to treatment, therapy, regular meetings with doctors, a team to support and monitor improvement, and basic rehabilitation.

No one leaves a place like Broadmoor, or any other secure hospital setting, without some sort of care package being in place. I moved to a medium security hospital, where I stayed for nearly two years. This was about rehabilitation, taking increasing responsibility for yourself, making trips into town for what might be the first time in a number of years. Next was low security, a local open unit where I began to get leave to go out of the grounds on my own. It's possible to really begin life again at this stage. I began with volunteer work and then got

a job in the coffee shop, and started to going to the gym. Of course there are occasional setbacks, but that's why the care package is in place.

After that was a flat in supported accommodation, with Rethink. Small gentle steps might feel frustrating at the time, but in hindsight they were key in building confidence in my own ability to deal with things like applying for benefits and paying bills and council tax. It's extremely important that people with mental health problems are given this kind of support on leaving prison or hospital because the stress is enormous and can easily overwhelm and jeopardise fragile confidence and a mental state that has taken a lot of hard work to achieve.

Even now, after I have been absolutely discharged, my local team has issued me with a card that is now updated annually with all the support services telephone numbers and addresses should I need them. And here I am, older, still struggling with depression and personality disorders but equipped to cope with them and the ability to seek help if I need it. I've worked since hospital and I'm currently part way through a degree. I ride a motorbike and last year rode it across France, Switzerland and Italy with my boyfriend and friends. I've survived, and I never thought I'd live past the age of sixteen.

We have a real opportunity here to make an investment for the future. If we get this right we can make life altering changes for people with mental health needs, potentially cut re-offending rates amongst sufferers, and also, longer term, save money.



Recommendations

To achieve fair treatment now, we need:

A national policy framework

1. Plans to increase access to psychological therapies for depression and anxiety should be implemented in parallel with steps to increase access to psychological therapies for severe mental illness. An appropriate outcome measure should be developed.
2. Additional national outcome measures should be introduced that judge whether death has been prevented and recovery promoted, including:
 - 2.1 Mortality rates from physical health conditions for people with severe mental illness
 - 2.2 Suicide, attempted suicide and sudden unexplained death rates for people with severe mental illness
 - 2.3 Patient and carer reported outcome measures for crisis care
 - 2.4 Public attitudes to mental illness, as measured by the Department of Health's annual survey of attitudes to mental illness.
 - 2.5 The duration of untreated psychosis
 - 2.6 The rate of compulsion under the Mental Health Act
 - 2.7 Employment of people with severe mental illness
 - 2.8 Provision of information to carers
3. A national tariff through Payment by Results should be extended to mental health services.
4. The plan to incentivise health providers to reduce emergency re-admissions should include mental health trusts.
5. Services should be evaluated using the 'recovery star' and patient and carer reported outcome measures.
6. Budget allocations to GP consortia must reflect true costs of service provision, including forecast savings.
7. A national plan to up-skill GPs in commissioning for severe mental illness must be introduced, if GPs are to undertake this role.
8. Choice of NHS provider afforded to NHS patients through Choose and Book should be extended to include mental health service users.
9. The Quality and Outcomes Framework indicator on the severe mental illness register should be brought into line with registers for other health conditions i.e. remove the requirement to obtain consent to be registered.
10. National level Healthwatch should focus on the needs of vulnerable patients with severe and enduring conditions, such as severe mental illness.
11. The requirement to report deaths to the Coroner should be extended to include those where the deceased has recently been detained under the Mental Health Act.

Delivery

1. New commissioning guidance on psychological therapies for severe mental illness should be developed.
2. Health professionals should undertake evidence-based mental health awareness and anti-stigma training, such as Education Not Discrimination, to facilitate shared decision-making.
3. Local level HealthWatch should have a role in monitoring local NHS trust complaints.
4. National outcomes data should be published (by trust) to allow benchmarking and comparison, increasing transparency.

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For reasons of confidentiality the testimonials used do not always relate to the individuals photographed in this report.

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Working together to help everyone
affected by severe mental illness
recover a better quality of life

About Rethink

Rethink, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life.

We provide hope and empowerment through effective services and support to all those who need us, and campaign for change through greater awareness and understanding.

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