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PURE MADNESS: HOW FEAR DRIVES THE MENTAL HEALTH SYSTEM

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FACULTY OF PUBLIC HEALTH MEDICINE ANNUAL SCIENTIFIC CONFERENCE 2002

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The killing of Jonathan Zito by Christopher Clunis, a man diagnosed with paranoid schizophrenia, on 2 December 1992 marked a watershed in the history of mental health care in Britain. Up to that point, the focus of concern had been on the welfare of patients discharged into the community as the huge Victorian mental asylums closed. Many were living impoverished lives in dingy bedsits and seaside boarding houses, forgotten and ignored. Stories exposing their plight had shamed politicians and the public and fuelled doubts about the hospital closure programme.

After the Zito killing, the nature of the debate about mental illness changed. The focus shifted from the care of the patients to the protection of the public. The psychopathic murderer – the 'mad axeman' of popular myth – became the new monster in our midst. 'Risk avoidance' and 'public safety' became the new watchwords. The switch of emphasis had an enormous impact on the care of people with mental health problems. Concern about the welfare of the many was replaced by fear of the risk posed by the few.

There are an estimated 600,000 people in England with severe enduring mental illness, most of whom have a diagnosis of schizophrenia or manic depression, but less than 1 per cent of them (4000 people in England) are judged as needing intensive care because they pose a risk to themselves or others. Most are at risk of suicide, not homicide, and it is important to recognise what a small proportion – about one in 10,000 – of the whole population they are.

Nevertheless, the rare cases of homicide involving mentally ill people have dominated the debate about community care, and it is easy to see why. It was not the killing of Jonathan Zito that was shocking, tragic as that was, for we are used to violent death. What was shocking was its randomness. It was a pointless, motiveless crime and it tapped our deepest fears about people with severe mental illness – the 'nutters on the loose' of popular prejudice.

At Clunis's trial on 28 June 1993 at the Old Bailey, the judge, Mr Justice Blofeld, accepted his plea of not guilty to murder but guilty to manslaughter and ordered that he be detained in Rampton high security hospital. In passing sentence, Mr Blofeld said: 'There must be no question whatever of your being released while there is the remotest chance of your being any danger to your fellow human beings.'

Six months later, the Ritchie Inquiry into the killing, published in February 1994, delivered a savage indictment of the care Christopher Clunis had received and said the blame should be shared collectively by all the agencies involved.[1] For more than five years he had been shunted between hospital, hostel and prison as his mental condition deteriorated and his violence increased, but no plans had been made for his care and there was inadequate supervision by doctors, social workers and police. 'It was one failure or missed opportunity on top of another,' the report said.

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[1] *Inquiry into the care and treatment of Christopher Clunis*, HMSO, 1994.

Although the Ritchie Inquiry endorsed the community care policy, which it said worked well for the vast majority of mentally ill people, in a crucial passage it warned that there was a serious risk that repeated violent attacks by mental patients would discredit the policy and that ‘exceptional means’ were required to prevent them. ‘The serious harm that may be inflicted by severely mentally ill people to themselves or others is a cost of care in the community which no society should tolerate.’

That sentence, with its unequivocal warning, has been ringing in the ears of policy makers and practitioners ever since. It was the signal for a new, coercive approach to the care of people with mental health problems. Subsequent inquiries into killings by mentally ill people followed the Ritchie report’s lead, calling for tighter controls on patients – to the disquiet of psychiatrists, who protested they were being turned into jailers. Supervised discharge, registers of dangerous patients, increasing detention, and a psychiatric service driven by fear of further killings were the result.

Where is the evidence that the mental health system is becoming more coercive? The number of people forcibly admitted to psychiatric hospitals has risen by half in a decade. The total stood at 26,700 in 2000–01, up from 18,000 in 1990–91. These are people whose liberty has been removed even though the vast majority have committed no crime. Unlike prisoners, they have been forced to accept treatment, including drugs and ECT, which in any other circumstance would amount to an assault. This is the clearest measure of a system driven by fear – fear of what these people may do to themselves or others.

In addition to these formal admissions to hospital, a further 20,500 patients were formally detained under the Mental Health Act 1983 after admission to hospital as voluntary patients. That figure, too, is sharply up on the number ten years ago. So in 2000–01, the total number detained in hospital stood at 50,000, around 20,000 more than a decade earlier. In keeping with these trends, the number of beds in secure units has more than doubled, from less than 1000 in 1991–92 to 2000 in 1997–98.

Why the increases? Dr Roger Freeman, Chair of the Parliamentary Committee of the Royal College of Psychiatrists, has a simple answer: ‘It probably reflects less permissive attitudes in society rather than any changes in mental health problems.’

The same view was put forward by researchers from the Department of Psychological Medicine at Guys, Kings and St Thomas’ medical school, in a study charting the rise in compulsory admissions. The report suggested that the increase in drug and alcohol abuse by psychiatric patients and the fall in hospital beds were also factors. It said: ‘The public’s fear of violence by mentally ill patients and pressures to keep patients in hospital until it is ‘safe’ to discharge them put further strain on the availability of beds.’[2]

The Mental Health Act Commission (the independent body that monitors mental health services) suggested that one reason for the increase in detentions following voluntary admission might be that patients ‘have to be coerced to stay’ – a grim comment on the dreadful state of most in-patient wards.[3]

Do these people need to be detained? Not according to the Mental Health Act Commission. Margaret Clayton, Chair of the Mental Health Act Commission, highlighted in her foreword to its Ninth Biennial Report (December 2001) the ‘huge variations’ in the quality of provision for detained patients. ‘A high proportion of these patients would not need to be detained if satisfactory health and social care were available in the community,’ she wrote. Almost exactly the same points were made in the Eighth Biennial Report and in those that preceded it.

Official figures show a sharp rise in the prescription of anti-psychotic and anti-manic drugs in the community, up from 3.5 million prescription items in 1991 to 5.9 million in 2000 – a 66 per cent increase in a decade. Partly this reflects the growing numbers of mentally ill people treated in the community, but there has also been a real increase in prescribing.

The cost of the drugs has risen almost sevenfold over the same period, from £15 million in 1991 to £100 million in 2000, as the newer atypical anti-psychotics have been increasingly prescribed. In 2000, atypicals, which are said to have fewer side effects, accounted for 1.1 million of the 4.9 million prescriptions issued for anti-psychotics, 23 per cent of the total.[4] With the recent Nice guidance giving the green light for the prescription of atypicals, costs will rise further – but, paradoxically, this may help those campaigning for less use of drugs. As prescribing costs rise, the relative expense of other forms of treatment, such as cognitive therapy (which is greatly preferred by patients but very hard to get), will fall.

People with mental problems need a seamless service with all levels of support, but what they get is a patchy service with good support at certain levels and nothing at all at other levels. A researcher who studied the home treatment service in Manchester found people liked it when they got it, but complained they only got it when they had a crisis. There was nothing to prevent the crisis occurring.

In a similar way, in-patient treatment was welcomed by some as a sanctuary, a place of safety where recovery could take place. But when they were discharged again

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[2] Wall, S et al, ‘Trends in the use of the Mental Health Act: England, 1984–96’. *British Medical Journal*, 5 June 1999.

[3] *Ninth Biennial Report*, Mental Health Act Commission, December 2001.

[4] *Prescription Statistics*, Department of Health, 2000.

there was nothing – no support, and no help other than an out-patient appointment in four weeks' time.

Most suicides occur on the day after discharge from hospital, according to the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness.[5] The Government has set a target of reducing suicides by a fifth by 2010, and from March 2002 all patients with a history of severe mental illness must be seen by a professional in person within seven days of discharge.

Again and again, on my travels round the country to research this book, Pure Madness: How fear drives the mental health system (Routledge, November 2002), I heard stories about the difficulty of getting help. People with mental health problems wanted to get hold of the services they needed, when they needed them. Flexibility and accessibility were the keys. But the response of the professionals was uniform – the service had to be rationed, in practice, to those who posed some kind of threat. 'There is a sea of distress out there,' a manager in Norfolk told me. 'If we have open access, we will be overwhelmed.' A psychiatrist said: 'I will do my best for the 5 per cent most severely affected – not for the most vociferous or articulate or best at demanding services.' The most serious charge against the community care policy is that it has increased the number of homicides by letting loose 'dangerous lunatics' who ought to be locked up on a psychiatric ward.

What I found was a service driven by fear, in which the priority is risk reduction through containment by physical or chemical means. In every contact with a person with mental health problems, the question uppermost in the professional's mind is: 'Will this person kill themselves or someone else?'

The results are that:

- It's a crisis service – with little prevention or after care.
- It focuses on protection of the public – homicide is feared more than suicide.
- Fear of what the patient might do inhibits consideration of what the patient might need.

Despite our growing anxiety about people with mental health problems, there is no evidence that they commit more crime than anyone else. Figures show that there has been no increase in killings by people with a mental illness in the 40 years during which the mental hospitals have been emptying.

The argument that the community care policy has increased risks to the public cannot be sustained. Fewer than one in ten murders is committed by someone with a mental disorder, and over the last four decades people with mental health problems have accounted for a diminishing proportion of all homicides as the overall murder rate has risen.

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[5] *Safety First*, Department of Health, March 2001.

Ten times as many people die at the hands of so-called ‘normal’ people, most as a result of domestic disputes, as are killed by people with mental problems. Drunkenness causes more violent death than mental illness – yet we view drunkenness with amusement while we recoil from mental illness with fear. About ten times as many mentally ill people take their own lives as harm others – but suicides do not make the news. Yet the public and political focus on the tiny numbers who do pose a risk has distracted attention from the plight of the huge majority of frightened, disturbed people whose suffering remains largely hidden from an uninterested world.

Mental health staff are mostly highly skilled, caring and committed, but they are constrained in reality by a shortage of resources and by a treatment culture that places public safety above individual care.

So why has our fear of mentally ill people increased? Professors Thornicroft and Goldberg say: ‘We live in a society in which traditional sources of predictability and reassurance are breaking down. We have free-floating anxieties which we need to crystallise upon “monsters” in society. These may be paedophiles or they may be the mentally ill. But this is a society where we decreasingly want to take any risk … we are entering a period where it may be culturally easier to exclude than to include people who have any stigma attached to them which is associated with risk.’

One reason why mental illness has come to be linked with violence is because of the expanding remit of psychiatry and the social context in which most psychiatric patients live. Major studies have failed to show a link between mental illness and violence, or only a modest association, except when combined with alcohol or drug abuse.

Until the Second World War, alcohol and drug abuse were seen as morally degenerate and were criminalised, but from the 1960s onwards they were medicalised and brought within the ambit of psychiatry. Professor David Pilgrim, Head of Adult and Forensic Psychology services at Lancashire Mental Health Trust, suggests that this accounts for the linking in the public mind of mental illness with violence, although the link is actually closer with drugs and alcohol than with mental illness: ‘Compared to other variables (young age, low social class, unemployed status, male gender, history of violence) mental state per se is a weak predictor of dangerousness.’[6]

Psychiatric patients are also less likely to be in work than the general population, so they tend to live in poorer areas where alcohol and drug abuse and crime are more common. Thus, they are more prone to these conditions because they are more

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[6] Thomas Szaz, ‘Mental Disorder and Violence’, *Journal of Mental Health*, in press.

exposed to them. Their environment rather than their mental state influences their behaviour.

We are more tolerant of some kinds of dangerous behaviour – driving fast, drunkenness – than of the irrationality associated with mental illness. Our inconsistency towards dangerousness was captured by Thomas Szaz 40 years ago: 'Drunken drivers are dangerous both to themselves and to others. They injure and kill many more people, than, for example, persons with paranoid delusions of persecution. Yet people labelled paranoid are readily commitable, while drunken drivers are not … Some types of dangerous behaviour are even rewarded … Thus it is not dangerousness in general that is at issue here but rather the manner in which one is dangerous.'[7]

There are four key factors that have sustained this risk avoidance agenda in mental health in the decade since the Clunis case:

- the pressure from carers' organisations, which used the rare cases of homicide to keep the plight of mentally ill people in the public eye
- the stigma attached to mental illness
- the Government's decision to order an independent inquiry into each homicide involving a mentally ill person
- the role of the press.

Carers

After the death of Jonathan Zito, his widow Jayne (a former mental health worker with expert knowledge of the system) campaigned for better control of people with severe mental illness and better protection for the public, through the charity the Zito Trust, which she founded. She was a passionate advocate of her cause in whom grief and indignation were equally mixed – and she was young, blonde and attractive. The cameras loved her. In one famous incident, Jayne Zito ambushed the then Secretary of State for Health, Virginia Bottomley, who had refused her an interview. The interview was granted, and the ensuing publicity moved mental health sharply up the political agenda. Ms Zito was awarded an OBE in the 2002 New Year honours – an indication of how far her safety agenda is now shared by the Government.

Marjorie Wallace, the former journalist and founder of the charity SANE (Schizophrenia: A National Emergency), also took up the theme of tighter control of mentally ill people. In the mid-1980s she had exposed the dreadful neglect of patients discharged from mental hospital to eke out a half-life in the outside world, in a series of articles for *The Times* critical of the community care policy. It began under the headline 'When freedom is a life sentence' (*The Times*; 16 December,

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[7] *Law, Liberty and Psychiatry*, Macmillan, 1963, quoted by Pilgrim.

1985). Although the Zito case shifted attention from the safety of the patients to the safety of the public, Ms Wallace was happy to back the new agenda because it fitted with her campaign to win back asylum for severely mentally ill people. With her journalistic background and network of contacts, she gained the ear of ministers in a manner that caused envy and irritation among rival mental health charities.

Stigma

Whenever I raised the subject of community care for mentally ill people in conversation, it provoked the same response: mentally ill people can be scary, in the way they look and the way they behave. We cannot wish away the stigma merely by asserting it unjustified, in the face of people's personal experience.

The director of a leading mental health charity told me that people with mental problems cannot realistically claim parity with blacks and gays, as some of them would like, in their anti-stigma campaign. He said: 'What is the message here? That mentally ill people are normal? But they are not. I am afraid of a schizophrenic on the street having a crisis. It is frightening and we have to acknowledge that. It is actually a very serious illness with many problems, that devastates lives and families. You can't say that about being black, or gay – that is racist or homophobic. OK, so people with schizophrenia do not kill babies in cold blood – but it is more complex than the supporters of Mad Pride [a user group] suggest – reclaiming the language in the way Gay Pride did.'

The key question is what we do about the oddity we witness in people with mental health problems. In the first place, most of them for most of the time are no more odd than anyone else. Even when they are, is that a justification for locking them up or forcibly treating them with drugs?

Oddity in all its forms was incarcerated in the nineteenth century – including people with epilepsy, mental handicap, and 'moral degeneracy'. We now like to think we take a more liberal and enlightened view of these differences. Some people find black people threatening, but we do not lock them up without evidence of illness or wrong doing (although they are over-represented in both the penal and mental health systems).

Only by keeping people in touch with services do we stand a chance of preventing breakdowns with their rare but occasional violent consequences. As John Mahoney, joint head of mental health at the Department of Health put it to me, 'If we develop services that people don't want to use, they won't use them – and we can't bang up all 600,000 people in the UK with severe mental health problems.'

The Mental Health Act Commission commented: 'The assumption that people with a psychopathic disorder are likely to be a risk to the public seems to be based on media hyperbole about the very small number of such people who have committed serious offences. Where there has been a public inquiry into such cases the failure has more often been in the non-use of existing services than in the absence of legislative provision.'[8]

Inquiries

Each new tragedy was followed by an official inquiry that guaranteed that it received maximum public and political attention. Until the 1980s, it had been the institutions that were in the limelight as scandals erupted with regularity, from Ely hospital in 1969 through Whittingham and Normansfield to St Lawrence's in 1981. From the late 1980s, the focus shifted to community care tragedies.

In 1994, following the Ritchie report, the Department of Health ordered that an inquiry should be held into every case of homicide involving mental health services. According to the Zito Trust, by 2002, more than 120 such inquiries had been established.

The result was what professionals have described as an 'inquiry culture', in which staff were made aware that 'any variation from recommended perfect practice could lead to an unpleasant afternoon in front of a cynical inquiry panel and the humiliation of being named in a report.'[9] Inquiries were seen as a threat rather than a corrective mechanism; they encouraged a 'safety first' attitude, and fostered the mistaken impression that every disaster was preventable.

Media

Each new killing by a mentally ill person received wide coverage by newspapers eager for new scares with which to shock readers – and the subsequent inquiry provided a second opportunity to revisit the crime. Lurid headlines – 'Schizo killer was a bomb waiting to explode', 'Doc freed psycho to kill' – stoked the flames of public outrage. Community care killings on the continent have never received the same level of publicity, though they happen with similar frequency. The press played on the association between irrationality and aggression, because unpredictable threat is feared more than that which is anticipated. But it ignored other causes of danger, such as drunkenness, and took no account of the needs or civil liberties of those whom it wished to see contained.

The 1996 attack on Lisa Potts, a nursery teacher, in which seven children were severely injured by a deranged man, Horrett Campbell, wielding a machete, lifted

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[8] *Ninth Biennial Report*, Mental Health Act Commission, December 2001.

[9] Matt Muijen, in *Mental Health Matters*, edited by Tom Heller et al, Open University, 1996.

concern to fever pitch. This was followed the same year by the gruesome killing of Lin and Megan Russell on a woodland path near Chillenden, Kent, by Michael Stone, diagnosed with severe personality disorder, who left nine-year-old Josie maimed but alive.

The Michael Stone case proved to be the final straw for the Government. The disturbing allegation that Stone had been discharged from care because psychiatrists considered he was not treatable provoked outrage. Ministers declared that public safety must be paramount. The community care policy came under fire for allegedly dumping 'dangerous lunatics' on to the streets without support. In 1998, the tide of criticism reached a peak when Frank Dobson, then Secretary of State for Health, stood up in the Commons and declared: 'Community care has failed.'

Rise of the users' movement

It was not always like this. Professionals say that it is only in the last five years that the pressure from a Government and public that is averse to risk, and bent on pinning blame when things go wrong, has produced a culture of containment in the mental health services. This can be seen in rising detention, increasing use of medication, locked wards and growing dissatisfaction among the users of the services. While public safety and the avoidance of risk drives the service (fuelled by fear and political opportunism), the demand from the people who use the service for more involvement and control, more 'ownership' of their problems and treatment, is rising to a crescendo.

The biggest change in the last decade has been the growing protests from people with mental health problems who use the services. There is enormous dissatisfaction with the treatment offered, with the emphasis on risk reduction and containment and the narrow focus on medication. They dislike the heavy doses of anti-psychotic and sedative drugs, with their unpleasant side effects, and a growing number reject the bio-medical approach which defines their problems as illnesses to be medicated, rather than as social or psychological difficulties to be resolved with other kinds of help.

As the numbers detained in hospital have soared by 50 per cent in a decade, the protests have grown louder. The rise of the users' movement is the single most striking development in the mental health services in the last ten years. A plethora of groups representing different user interests have sprung up, magazines such as *Openmind, Asylum and Breakthrough* are flourishing, and there is increasing professional support. People with mental health problems are demanding a greater say in their treatment and a wider range of options from which to choose.

It is not sufficiently recognised that much severe mental illness is episodic, in which periods of acute psychosis, mania or depression are interspersed with periods of relative calm. Someone with schizophrenia, for example, is not permanently disoriented or confused, as someone with a brain injury or Alzheimer's disease is. During the periods of calm, the affected individuals are fully capable of running their own lives – and making plans to cope with the next crisis.

Thus, they want to be taken seriously rather than ignored, to be involved in decisions about their care and to be offered a range of options, from crisis houses to support groups to new strategies for living that go beyond treatment with drugs. Above all, they object to being typecast as 'dangerous' on the basis of the violence of a few, and claim that this is as discriminatory as blaming all black people for the actions of the occasional black criminal.

The Government's response has been confused as it has tried to face in two directions at once. To people with mental health problems, it has presented the compassionate face of New Labour, embarking on what the Mental Health Act Commission has described as the quickest and most dynamic transformation of policy in the history of state intervention in mental illness.[10]

Mental health has been designated one of the top three health priorities, along with cancer and heart disease. There is a new National Service Framework, a mental health czar and a new drive to roll out intensive community care services nationwide, backed by £300 million of new investment over three years from April 2002. If it can be successfully implemented, the programme promises real improvements for mentally ill people.

The heart of its strategy is a major boost to community care that will involve, by 2004, creating 335 crisis resolution teams working with people in their homes and 220 assertive outreach teams to keep in touch with hard-to-engage clients, such as drug users with mental problems. These will serve 100,000 people a year who would otherwise have to be admitted to hospital, reducing the demand for beds by an estimated 30 per cent, and will provide support for about 20,000 of the most difficult clients.

In addition, early intervention teams will be set up, offering a specialised service to people under 35 who have developed psychosis, to cut the average 72 weeks that they have to wait for diagnosis and treatment. Some studies suggest that early intervention in schizophrenia can shorten the course of the devastating illness and lessen its impact.

The Mental Health Act Commission has commented that 'National policy on mental health has developed more quickly and more dynamically [over the previous two

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[10] *Ninth Biennial Report*, Mental Health Act Commission, December 2001.

years] … than at any time in the history of state intervention in mental illness.' While this looks like an accolade, it could also be interpreted as an indictment of the lack of progress in the previous decade.

The aim of all this activity is summed up by the leaders of the Government's strategy, John Mahoney and Antony Sheehan (joint heads of mental health at the Health Department) thus: 'People say community care has failed. We say it has never been tried.'

Politicians are also sceptical. In February 2002, Oliver Heald, Tory spokesman on health, obtained parliamentary answers from Jacqui Smith, Minister for Mental Health, which showed that progress towards achieving the targets set out in the NHS Plan was slow. Only 16 of the 50 early intervention teams promised by 2003–4 had been set up, and only 52 of the 335 crisis teams. 'Here we are halfway through the time with far less than half the services in place,' he said.

That is the face the Government has presented to service users. But to the public, the Government has presented its authoritarian face, capitalising on the alarm caused by random attacks, such as the killing of the TV presenter Jill Dando and the assault on former Beatle George Harrison, with proposals for a new, heavy-handed law to deliver a safer service, billed as the biggest change to mental health legislation for 40 years.

The authoritarian instincts of the Labour Government were laid bare when it published its White Paper *Reforming the Mental Health Act* in December 2000. The paper contained tough new proposals to treat mentally ill people forcibly in the community if they stopped taking their medication and to lock up 'high risk' people with dangerous severe personality disorder. Described as the biggest reform of mental health legislation for 40 years, its emphasis on the dangers posed by people with mental problems alarmed users of the service. Groups representing mentally ill people complained that the plans would increase coercion, and psychiatrists protested that they would turn them into jailers. At this point in time, a mental health Bill was still awaited.

The thrust of the proposed new law was made clear in the foreword to the White Paper, signed jointly by the Health and Home Secretaries, Alan Milburn and Jack Straw: 'Public confidence in care in the community has been undermined by failures in services and failures in law. Too often, severely ill patients have been allowed to drift out of contact with mental health services. They have been able to refuse treatment. Sometimes, as the tragic toll of homicides and suicides involving such patients makes clear, lives have been put at risk. In particular, existing legislation has also failed to provide adequate public protection from those whose risk to others arises from a severe personality disorder. We are determined to remedy this.'

Publication of the proposals provoked widespread dismay. The Royal College of Psychiatrists said it ‘gives the impression of a radical shift in balance towards social control and risk management and away from therapeutic concerns. It is extremely likely that this process would deter patients from seeking medical treatment for a mental disorder.’[11]

Ministers, playing on the public alarm over the rare community care tragedies, showed they were prepared to be tough on any threat to individual or public safety. Paul Boateng, then Junior Health Minister, captured the mood when he declared (referring to the failure of some mentally ill people to take their medication): ‘We will not tolerate a culture of non-compliance.’

Forced injections in the community

One theme recurs through the homicide inquiries over the past decade like a tolling bell. In case after case, the final, lethal attack occurred after the mentally ill man (for it is almost always a man) had stopped taking his medication.

Mental health campaigners say it is a measure of how unpleasant the drugs are, with their nasty side effects, that non-compliance is a major problem. If the treatments are so good, they say, why do patients reject them? Most psychiatrists take the opposite view. It is because the drugs are successful that patients feel better, they argue – so much better that they think they can do without the drugs.

The Government has decided that the problem of non-compliance must be confronted, and the way to do it is to extend the powers now available to doctors to administer treatment forcibly.

In its 2000 White Paper,[12] the Government said: ‘At the moment clinicians have to wait until patients in the community become ill enough to need admission to hospital before compulsory treatment can be given. This prevents early intervention to reduce risk to both patients and the public. We will therefore introduce new provisions so that care and treatment orders may apply to patients outside hospital. This will mean that patients need not be in hospital unnecessarily and need not suffer the possible distress of repeated unplanned admissions to acute wards.’

However, these new proposals mean, in effect, that patients will be detained in the community – an idea about which many patients and professionals feel uncomfortable. In the past, patients have always been able to hold their heads high when they left hospital. Professionals fear that extending compulsion into the sanctuary of people’s homes will undermine the bond of trust that is essential for

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[11] Letter to Jacqui Smith, Health Minister, from Professor John Cox, President, 13 July 2001.

[12] *Reforming the Mental Health Act*. White Paper. Labour Government, December 2000.

effective treatment to take place. Mental health user groups warn that the new provisions will drive users away from services.

The Royal College of Psychiatrists is split on the issue. Its President, Professor John Cox, said: '[Care and treatment orders] could lead to more rather than fewer patients being detained. They would have to be at a certain place at a certain time and allow a nurse to come into their front room or wherever and give them an injection. That is quite an extension of coercive powers.'

In summary, there must be serious doubt whether imposing a new law will improve compliance with treatment. Clamping down in an authoritarian way on a vulnerable group is discriminatory and cannot guarantee that the tiny minority who become violent without their treatment will continue to take it.

The key requirement for community treatment is that it must ensure that care meets the individual's needs in the least restrictive setting. New legislation could prove a valuable way of keeping people out of hospital if combined with other help – social, financial or work-related – providing some structure to their lives. But the Government seems bent on extending coercion without providing the structure that leads to (self) control.

'Structure is what people want,' said Margaret Clayton, Chair of the Mental Health Act Commission. 'Care is very much about structure. If you say structure is control, care and control are not divisible.'

Locking up the highly dangerous

When Michael Stone was convicted on 4 October 2001 of the murder of Lin and Megan Russell and the attempted murder of Josie Russell, there was widespread relief that a line had been drawn under one of the nastiest crimes of the last century.

It was only after the killings, during the police investigation, that the most disturbing detail emerged. Stone, a man with a violent past, had been diagnosed with an anti-social personality disorder and was well known to the mental health services. But psychiatrists had said he could not be detained under the Mental Health Act because he was not mentally ill.

The Government devoted the second half of its December 2000 White Paper[13] to 'high-risk patients', proposing that those deemed a serious risk to the public should be detained. In a key passage, it said that new criteria for compulsory treatment would be introduced, which would 'provide clear authority for the detention for assessment and treatment of all those who pose a significant risk of serious harm to

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[13] *Reforming the Mental Health Act*. White Paper. Labour Government, December 2000.

others as a result of a mental disorder.' This would be achieved, it said, 'by dealing separately with those who need treatment primarily in their own best interests and those who need treatment because of the risk that they pose to others.'

The row is unlikely to go away, however, because the issue of personality disorder highlights a fundamental dilemma about mental illness. Are people like Michael Stone mad, or are they bad? If they are mad, they deserve care and treatment from psychiatrists but if they are bad, who should be responsible for them? Psychiatrists resist being cast as jailers.

The proposals have generated fierce controversy. Professor John Cox, president of the Royal College of Psychiatrists, said: 'It is not our job to cure society's ills. Our job is to treat people and get them better. We are not containers of people whom we can't do anything to help. The idea that it is our job to modify unwanted behaviour brings psychiatrists too close to being agents of the State whose job is to modify behaviour the State doesn't like. We don't want to collude with the State and we don't want political interference with professional judgement.'

This view was echoed by Margaret Clayton, Chair of the Mental Health Act Commission and a former director of the prison service: 'The White Paper goes close to laying the foundation for social engineering – "We don't approve of this behaviour, so we lock you up."'

Even if the professionals could be persuaded to co-operate, could the 2500 highest-risk people be rounded up and detained? Officials believe they could. One manager said: 'Most mental health teams know who they are – they have one or two in their patch and they are scared of them. I know two. When you look back, they are often those who microwaved the cat as teenagers – they have a record of cruelty. Most are already locked up in prison or high-security hospitals, but there are perhaps 400 out in the community. They are scheming paedophiles, some of them; and some have already killed, but there may not be enough evidence to convict or to keep them in jail.'

Clayton rejected this view. 'If you talk to any Chief Constable, they will tell you they could pick out the serious criminals on their patch. But if we are not allowed to pick up criminals [without the evidence to convict], why should we allow it for the mentally disordered?' She added: 'But the Government is doing it for terrorists [post September 11] – picking them up and detaining them on the balance of probabilities. They are undermining the whole culture [of being innocent until proved guilty] in this country.'

The legal advice received by the Government is that a person can be detained under the Mental Health Act if they are being treated. The issue then turns on what counts as 'treatment'. Treatment must make a difference to a patient's condition. But would a small improvement count? Or what about stopping deterioration?

On this basis, it might be possible to detain someone if it could be shown that detaining them would prevent their continued deterioration. But this could lead to a situation where it would be legal to detain those patients who were improving or remaining stable, while those who were deteriorating would have to be discharged on the grounds that they could not be treated. The absurdity of that outcome highlights the difficulty with drafting the proposed Bill.

Psychiatrists have always made judgements about who is dangerous, and – despite their protests – have always been involved as agents of social control. ‘That is one of the functions of psychiatry – to protect the public,’ said Professor Louis Appleby, National Director for Mental Health (England and Wales).

How accurate are these judgements? Setting aside the moral question of whether it is ethical to detain people who have committed no offence for the protection of others, is it possible for psychiatrists to predict who is liable to be violent?

In most cases, the judgement involves nothing more scientific than going in, talking to the patient, reading the notes and coming up with a clinical opinion. It relies on the charismatic authority of the psychiatrist – and psychiatrists have very divided opinions.

George Szmukler, Dean of the Institute of Psychiatry, has argued that homicide, and even suicide, are such rare events, that they are impossible to predict accurately. The risk of any violence (pushing and shoving) in patients with psychosis is 6 in 100. For serious violence it is 2 in 1000. For homicide it is 1 in 15,000. ‘These are incredibly rare things – there is no possibility of predicting them, and no test could be sensitive enough to pick up such rare events without falsely charging dozens of others,’ he said.

This message was driven home in a paper by Alec Buchanan and Morven Leese of the Institute of Psychiatry, London,[14] based on 23 published studies of dangerousness. It concluded that to prevent a single violent act in a year, six psychiatric patients would have to be detained throughout the period.

In a commentary on the finding, Frank Farnham and David James[15] delivered a ferocious attack on the Government’s plans: ‘The forecasting of dangerousness remains like that of the weather – accurate over a few days but impotent to state longer term outcome with any certainty.’ They added that with the sharp rise in compulsory admissions in the last decade, psychiatry had already become more coercive: ‘It now threatens to assume an Orwellian air as the socially undesirable risk indefinite incarceration in psychiatric (or pseudo-psychiatric) institutions.’ They said

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[14] *The Lancet*, 8 December 2001, p1955.

[15] *The Lancet*, 8 December 2001, p1926.

that the changes reflected a gradual transformation in social policy and criminal justice as the ‘culture of welfare’ was replaced by the ‘culture of control’.

However, the impossibility of predicting very rare events is not the only problem. A crucial flaw in the Government’s position was highlighted in an earlier paper by George Szmukler and Paul Appelbaum.[16] If ‘high-risk’ patients are to be detained for the protection of the public, rather than in their own best interests, then the key factor determining who is detained should be dangerousness rather than mental illness. But on that ground, drunks or men who regularly beat their wives should be locked up. People with mental problems commit a very small proportion of all serious violence and the proposed detention of mentally ill people is therefore discriminatory.

Szmukler’s view is that predicting suicide is equally impossible. ‘Let’s concentrate on treating illness and alleviating suffering, not on the illusion of risk management. There is an enormous amount of energy going into these areas,’ he said.

The best chance of saving lives (by suicide and homicide) and producing a safer mental health service, therefore, is to secure the engagement of the people who use them. ‘Make services as acceptable and attractive to users as possible,’ say Szmukler and Appelbaum.

So how do we do that? Community care is 40 years old but we are only just beginning to understand what it means. It is not just about providing small-scale accommodation in the community – though that is largely what it has consisted of. Belatedly, we have come to realise that community care involves a range of measures to promote social integration. That means help with jobs, money, housing, relationships, neighbours and social skills. It means a focus on prevention and mental health promotion, rather than crisis intervention. It means replacing the language of sickness with the language of recovery.

Professor Antony Sheehan, Joint Head of Mental Health at the Department of Health, told a conference organised by the Sainsbury Centre for Mental Health in April 2001: ‘For too long we have had a pessimistic view of people who use mental health services. The expectation of chronicity in schizophrenia leads to learnt helplessness. We need a cultural and professional shift in attitudes.’ His vision for the future was of a service that was ‘user directed, family supporting, recovery oriented, clinically and culturally competent and cost effective’.

In reality over the last decade, mental health services have been driven by public and political pressure to adopt the risk-avoidance agenda. Facing a chronic shortage of resources, community care has never been realised in its full scope and the

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[16] Thornicroft G and Szmukler G, editors. ‘Treatment pressures, coercion and compulsion’. *Textbook of Community Psychiatry* 2001, OUP.

services have been narrowly focused on securing the safety of the public rather than meeting the needs of the individuals. The result is a service that:

- provides help in a crisis for people with mental health problems but offers little in the way of prevention to stop the crisis occurring, or support after it is over
- is medically driven and focused on drugs, with little choice of other types of treatment
- relies on containment and compulsion, with a 50 per cent increase in the sectioning rate in the past ten years and increasing use of medication
- is strongly disliked by the users
- has been more heavily influenced by carer's organisations
- is being driven to be more coercive and controlling by Government proposals for legislation highlighting dangerousness.

The argument of this lecture is that the most effective way to increase satisfaction and at the same time improve public safety is to devise services that genuinely engage mentally ill people and meet their desire for greater involvement in their care so that they are encouraged to seek treatment and lead stable, risk-free lives. When you ask people with mental problems what they want, they list the things that anyone would want in an emotional crisis – someone to talk to (loneliness is one of the greatest burdens of mental illness), a calm and safe place to be, and meaningful activity.

The way forward

The therapeutic relationship

So what does a mental health service aimed at engaging the people who use it look like? The starting point has to be the therapeutic relationship between doctor and patient.[17] It should be based on a joint approach, in which the patient is given clear information on the disorder, its likely course and the treatment options. The patient then becomes a negotiator in their own treatment and can be given a degree of control. For example, if they have experienced unpleasant side effects from medication, they may be able to agree a reduced dose, or a dose range within which they have day-to-day discretion, or they may be able to plan jointly that no medication will be given unless certain symptoms occur.

The negotiating position can be extended to other areas, such as attendance at a day centre or applications for employment. 'The issue is the balance between the need to be directive in prescribing treatment recommendations … with a readiness to modify prescriptions in answer to patients' own preferences,' write Thornicroft and Tansella.

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[17] See Thornicroft G and Tansella M. *Mental Health Matrix*. Cambridge University Press, 1999.

‘It is our clinical impression that this more inclusive approach to patient involvement in treatment decisions does lead to improved compliance and that this renders relapse less likely. Patient participation may therefore be seen as both principled and pragmatic.’

A calm and safe place to be – the crisis house

Crisis houses are ordinary houses that offer an alternative to hospital. I visited Anam Cara in a leafy suburb of Birmingham. Open the front door and you are in a family home, with boots and coats in the hall, pictures on the walls, milk in the fridge, a cloth on the table and people to have a cup of tea with. Contrast with the bleak Elizabeth Ward at Highcroft Hospital: beds in rows separated only by curtains, featureless institutional rooms, no privacy, and no comfort.

Crisis houses would not be suitable for the seriously psychotic – but most people on the wards are not seriously psychotic. We need a range of provision, and that is what crisis houses provide – something between hospital and community care.

The power of talk

One of the most consistent complaints made by people with mental problems is that too little effort is made to engage with them. ‘Madness is when other people choose to stop trying to understand you,’ said Rufus May, clinical psychologist and former mental patient. The constant demand is for more talk – whether as formal therapy or just as someone to talk to. Mental illness is isolating, those affected are often friendless and lonely, and the stigma attached to the illness increases the alienation.

There is growing evidence that cognitive behaviour therapy (CBT), an established treatment for depression sometimes referred to as ‘positive thinking’, is also effective in schizophrenia.

Listening to the voices

Hearing voices is one of the classic symptoms of schizophrenia. The traditional approach to treatment has been to discourage the patient from engaging with the voices – so they are ignored. This approach was a cause of great distress. Thanks to the work of Marius Romme, the Dutch psychiatrist, it is now increasingly accepted that the best way of dealing with voices is to explore and negotiate with them, rather than trying to ignore them.

Today there are more than 100 self-help groups for voice hearers in the UK that assist people to live with their voices, rather than denying their reality. Julie Downs, who runs the Manchester office of one such group said: ‘Some feel persecuted, while others live with their voices comfortably. One person heard 50 voices. The way he coped was by trying to sort them out and give them names. Some people hear them from morning to night – others just occasionally. Some have them under control and are not distressed by them, but in others they come unasked, uninvited and they won’t go away. Our aim is to support people so they can fit their voices into their lives and are not stopped from doing things.’

Putting consumers in charge

In Newcastle, Professor Allan Young of the School of Neurosciences, at the Royal Victoria Infirmary, has experimented with giving people diagnosed with manic depression control of the anti-psychotic drugs used to treat manic episodes. ‘We have been teaching people to recognise their relapse signature – symptoms like sleep disturbance and paranoid ideas – so they know when they should start treatment. If you can nip it in the bud, you can stop the relapse going any further. Some patients have done quite well with it.’

Professor Young, who got the idea after having his appendix out and being offered patient-controlled analgesia to deal with the pain – a morphine pump which allowed him to choose how much of the drug to take – said in May 2002 that he was planning further trials. ‘If you have a more collaborative approach [to prescribing] you can increase compliance. People like it much more,’ he said.

Planning for a breakdown

One of the most frightening aspects of a mental health crisis is the uncertainty over what may happen once a person enters the mental health system. Which drugs in what doses will be given, who will be informed, what arrangements will be made to look after other members of the family, and so on? An advance directive, also known as a ‘crisis plan’ or ‘crisis card’ (though some run to several pages), spells out what a person finds helpful when he or she has a crisis and is in distress, and what is unhelpful.

It may cover any aspect of treatment, from which drugs in which doses work best, and whether treatment is to be delivered in hospital or at home, to what is to be done with the person’s dog while he or she is in hospital. For some people, worry about who is to look after the cat, dog or other pet is among the most distressing aspects of being admitted to hospital.

The directive should be agreed in advance with the person's doctor as it then provides the person with a measure of control. But even if agreement cannot be reached on all parts, it should always be achievable on some. Trials show that advance directives are extremely popular, providing users with a means of asserting themselves.

For Eleanor, the advance directive has helped convert her from a passive recipient of care into an active service user. She writes: 'I feel much more able to make psychiatric services work for me in a way I feel comfortable about, and much less likely to feel used and abused by these services as I did in the past.'

Paying for one's own care

The traditional way of providing community care is to offer clients support services, such as a few hours a week of counselling, advice or help with shopping. But this is often inflexible and geared to the needs of the organisation rather than the individual. An idea already well established among those with physical disabilities, is to offer people with mental problems the cash to buy their own support services.

Pauline Heslop[18] employs two personal assistants with the money she is given by social services – costing up to £200 a week, depending on need. She is one of the first mental health service users to go on to the direct payments scheme, though the system has been used for supporting people with physical disabilities since 1996, and an estimated 3500 have benefited from it.

Pauline has one assistant for a certain number of hours or nights each week, and the other as a back-up, to come in when she needs extra support. 'If I have a therapy session, hospital appointment or just a difficult day at work, in prospect I will prioritise cover for those days. The hours of work are flexible and generally planned a week in advance, according to what my plans are.' The arrangement gives her 'the confidence to live my life as I wish to live it rather than being constrained by fear, lack of confidence and low self esteem.'

The role of work

If you ask mentally ill people about employment, they say they want work, not workshops. Yet workshops – the sheltered kind – were for decades all that was on offer – and still are, in many parts of the country.

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[18] *The Advocate*, May 2001.

Unemployment among people with severe mental illness ranges from 61 to 73 per cent, according to a review of research in the *British Medical Journal*[19] – much higher than among people with other chronic illnesses, such as diabetes, arthritis and epilepsy. Unemployment not only cuts them off from meaningful activity – it also restricts their social lives. They don't meet people and they can't go out in the evening because they can't afford a drink in the pub.

In the US, the transitional employment programme is proving successful. It involves persuading firms such as McDonalds, the burger chain, to allocate three workslots to people from the scheme, and the scheme guarantees to fill them. It may have six people on its books for the McDonalds jobs and can rely on at least three being fit for work on most days. If not, other members of staff will go in and fill the workslots on any shift when no scheme member is available so that the employer is guaranteed continuity.

In the UK, mentally ill people are now part of the Job Brokerage scheme, formerly called the New Deal for the unemployed, under which employers are subsidised to take on those who have been out of work long term.

In some cases, schemes have made use of 'job coaches', who go in and work alongside the mentally ill person in the job, providing support. The evidence is that the outcomes in supported work programmes are better than in preparatory work programmes, where people are sent for training for a specific job before being launched into it. According to the BMJ research review cited above,[20] preparatory work programmes are still the norm in the UK but at least 80 agencies offer supported employment.

Nicola Harris of the National Schizophrenia Fellowship spent three months working two days a week in a college library in Essex as a job coach to her client, Lucy, while Lucy built up her skills and confidence. 'It has made a big difference to her life. She really enjoys it and her mental health is better. She is on disabled persons' tax credit, so she is better off than she was on benefits,' said Ms Harris. She added: 'It can be embarrassing having someone working alongside you to make sure you are coping, but Lucy wanted it. It was about building up her confidence and having a familiar face around that she could trust.'

Countering discrimination

According to Liz Sayce of the Disability Rights Commission, 'It is time that we stopped seeing mental health as only about service delivery. It is not just about what people need but what they can contribute. That is the meaning of citizenship.'

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[19] *British Medical Journal*, 27 January 2001.

[20] *British Medical Journal*, 27 January 2001.

The Commission was set up in 2000 to enforce the Disability Discrimination Act, 1996. As its Director of Communication and Change, Ms Sayce has seen the proportion of cases before employment tribunals involving people with mental problems rise to 23 per cent. She says a paradigm shift is required to view them not just as users of services but as contributors to society.

The benefits maze

One of the most direct ways of improving the quality of life of people with mental problems is to increase the incomes of the poorest. Evidence from one important study suggests that underpayment of benefits is so pervasive and extensive that the simple provision of benefits advice could have as much impact on people's lives as conventional medical care.

A study of 153 people in Croydon, conducted by the local branch of mental health charity Mind, found that their average income on benefits was £55 a week and 60 per cent of claimants were getting less than they should. So the allegation that they were 'scroungers' was hard to sustain.

Croydon Mind provided specialist advice to help people appeal. This was a long laborious and detailed process, which took up to 18 months. By the conclusion of the three-year study in 2000, their average income was £120 a week.

Rory O'Kelly, a benefits adviser and one of the researchers, said: 'The majority had no income other than benefits and a lot of them saw their income doubled. If this were repeated nationwide, maybe there would be less need for medication and hospitalisation.'

Patient involvement

The aim of these projects, and others like them, is to increase the autonomy and independence of people with mental problems so that they become more involved in their care and engaged with their communities – as neighbours, friends, customers and employees. What they represent is a new style of community care – user-driven, socially-integrated, recovery-oriented. From passive recipients of services, people with mental problems have become active negotiators, obtaining the best treatment available and contributing as full participants to their communities.

Conclusion

In reality, the services people with mental problems get are all too rarely like the cases cited here. Instead, they are focused on medication, containment and risk avoidance. Mentally ill people are feared because of their oddity, unpredictability and the threat – however rare – that they pose to public safety.

The clash between these opposing agendas is the subject of this book, Pure Madness: How fear drives the mental health system (Routledge, November 2002). At the start of the 21st century, the mental health services are under pressure both from within and without. The public and politicians want to be assured the services are safe and that they will protect them from the rare but catastrophic attacks of the kind suffered by Jonathan Zito. People with mental health problems want to be assured that the services are responsive and supportive, rather than coercive, and that they will include the patients as active partners in their care, rather than as passive recipients. But a coercive service whose priority is public safety is popular and vote-catching, while concern for civil liberties within a minority group – and one with a dangerous image – is not.

To brand mentally ill people as ‘dangerous’ is the worst kind of stigmatisation – and will increase their isolation and suffering. On those ethical grounds alone it should be resisted. Yet instead of positive messages about tolerating mental health oddity, the Government has put out messages that highlight its dangers. Ministers should be taking the lead in combating discrimination, not stoking it.

‘Care or control’ is the theme that has run through mental health policy for the last 200 years. Do we look after them or lock them up? On the one hand, the Government has shown its commitment to raising standards, increasing funding, reducing stigma and coercion and providing a more supportive and inclusive service. On the other, it has revealed a determination to protect the public, to clear the streets and to make the taking of medication ‘non-negotiable’ – a zero-tolerance, authoritarian approach, which will deter users from approaching services.

But there is a further, self-interested argument for resisting moves to brand mentally ill people as dangerous, and that is that the safest service is one that keeps in contact with the people it is supposed to help. Services that involve and engage people with mental problems offer the best protection for the public. Ethics and pragmatism thus fall satisfyingly together.

That is why there is an urgent need to build up services and roll out innovative ideas like the ones outlined above. Services must be designed around individual’s needs rather than requiring individuals to slot into existing services. The better the services for people with mental health problems, the better it will be for our communities. Improved public safety and greater user satisfaction go hand in hand.