

THE ABANDONED ILLNESS

A report by the Schizophrenia Commission

EXECUTIVE SUMMARY



November 2012

WHAT IS THE SCHIZOPHRENIA COMMISSION?

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

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

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

From the Chair of the Commission, Professor Sir Robin Murray, FRS

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

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

The inadequate care that many people with psychosis receive adds greatly to their distress and worsens the outcomes for what can already be a devastating illness. Most have a period in a psychiatric hospital unit but too many of these wards have become frightening places where the overwhelmed nurses are unable to provide basic care and support. The pressure on staff for increased “throughput” means that medication is prioritised at the expense of the psychological interventions and social rehabilitation which are also necessary. Furthermore, some wards are so anti-therapeutic that when people relapse and are in need of a period of care and respite, they are unwilling to be admitted voluntarily; so compulsion rates rise.

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

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

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

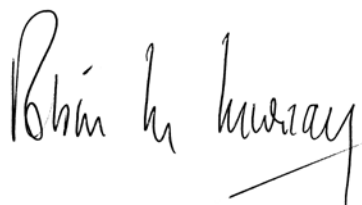
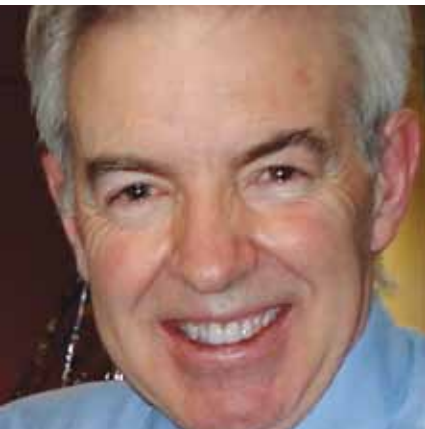
We welcome the Government's strategy 'No health without mental health' and the recently published implementation framework. There is broad agreement that services and the experience of those with the condition need to change. The cost of schizophrenia and psychosis to society is estimated at nearly £12 billion in England alone. But we are not spending the money wisely and not achieving the results that we could. If schizophrenia is approached with an understanding that substantial recovery is achievable for most people with the illness, instead of the defeatist attitude that this is the end of a person's useful life, then we can make a real difference. This is not an expensive fantasy but could lead to an overall saving for the country by turning users of services into contributors to the economy.

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

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

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

Our report sets out some practical steps to make this a reality.

A handwritten signature in black ink that reads "Robin Murray".

PROFESSOR SIR ROBIN MURRAY

on behalf of the Schizophrenia Commission

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

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



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

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

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

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

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

We have seen what can be achieved with innovative and creative solution focused approaches to care and treatment through early intervention in psychosis services. Today, instead of a life sentence, young people in early intervention services are given hope. They are supported to recover, with many returning to college or the workplace to live an ordinary life like everyone else. We want these outcomes for everyone living with schizophrenia and psychosis. We will not get them if this approach is dismantled by short term cost cutting restructures.

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

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

However, even if resources are not increased immediately, what's available now could be spent much more effectively. In particular, there is a case for a fundamental overhaul of secure provision, reinvesting savings in better community services and preventative programmes. And we could reduce expensive stays in acute units by providing cheaper and more therapeutic 'recovery houses'.

We visited a good example of this working in partnership with the local home treatment team. It offered time out from the pressure of living with severe mental illness among staff who valued each individual and their experiences. The place was calm, safe and practical. It sorted out people's accommodation difficulties. We need more crisis recovery houses to keep people out of hospital and help manage transition back into mainstream life on discharge from an acute care unit.

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

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

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THE COMMISSIONERS

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



**To read the full report from the
Schizophrenia Commission, go to
www.schizophreniacommission.org.uk**



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

For further information on Rethink Mental Illness
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