



rethink

severe mental illness

Reaching People Early

A status report on the early support received by people with severe mental illness and their informal carers.

Preface

The Rethink Challenge

This is one person's story, showing the huge benefits of reaching people early.

"I'm a twenty year old student studying at university. At the beginning of this year I experienced severe mental illness. After a three-month period of depression the onset of the illness came very quickly. After a period of 48 hours with no sleep I entered a paranoid psychotic state and attempted suicide.

Fortunately there was help at hand and I was taken to the local psychiatric hospital for assessment and treatment, this was obviously an extremely traumatic experience for me. After about a week of intensive medication and therapy I had calmed down enough for my father to take me out for day trips.

With the help of my father, my psychiatrist, the nurses and carers, my condition improved and I was granted leave after a period of 3 weeks in hospital. I spent this time with my father who helped me overcome my fears, delusions and paranoia. After a consultation it was decided that I was ready to become an outpatient and the next big step was to return to university, this was difficult and very frightening at first but as I realized that my fears were unfounded my anxiety and paranoia were cast away.

I was back at uni, attending lectures and catching up on my essays and in a week, had taken up sport again. Since then I have been back to the hospital to see my psychiatrist in the outpatient clinic and my medication has been reduced consistently.

Of course every case is different, it goes to show that with early intervention, the right medications, and family support, psychosis can effectively be managed and treated in a short period of time".

Rethink severe mental illness is the new operating name of the National Schizophrenia Fellowship.

Across all forms of health care, it is widely accepted that the sooner you identify a problem and treat it, the better prospects there are for recovery. That's why so much effort is being put into reducing waiting times and improving access.

Yet in mental health it takes, on average, up to 18 months for people developing severe mental illness to get specialist help. As a result, people become so ill that their first experience of care is often traumatic, and their long-term outlook is seriously damaged.

The causes are many. Stigma about severe mental illness means that people are often frightened to come forward for help. Misrepresentation in the media leaves most of the public unaware of what the early signs might be. Understanding amongst primary care professionals is poor. Families and friends who seek help and advice are often turned away. The services offered by the NHS to people with the early stages of mental illness are frequently inappropriate and off-putting – or even non-existent.

Rethink is determined to tackle the scandal of delays in care for people developing severe mental illness. We will undertake research, campaigns, and pilot ways of working to improve understanding and better meet the needs of people at this crucial early stage.

Our challenge to everyone involved in severe mental illness is simple and practical: get the right help to people at the right time.



Reaching people early is not just about helping people with first onset severe mental illness. It is also about getting help quickly if people experience a relapse later in their life. And it is about getting help and information to carers early. The sooner family and friends are informed and supported, the more they can do to help the person they love.

Every stage is crucial. If someone's first experience is positive and supportive, it is much more likely that they will seek help quickly if they start to experience a relapse.

Our society has become so used to poor outcomes in mental health care that professionals, politicians and public alike have come to expect no better. Pessimism is all pervading and holds back progress. Times have changed. Much more can be done with the best modern treatments and care delivered early. It's time for us all to rethink our attitudes towards severe mental illness and accept only the best.

Please read this report, visit the Rethink website at www.rethink.org and use the contacts and information. Join us in our campaign to reduce delays, reach people early, and increase everyone's chances of recovering a fulfilling life.

Thank you.


Jenny Fisher

Jenny Fisher
Chair.



Cliff Prior
Chief Executive.

Introduction

This report brings together facts, references and government policy targets, related to severe mental illness, in a structure based on a common "pathway" through mental health services. The pathway described is for someone who develops a severe mental illness like schizophrenia, manic depression (bi-polar disorder), or severe depression. At each stage along the path there are opportunities to "reach people early" and by doing so improve their quality of life and make the most effective use of the resources available.

Stages

Stage One:

good mental health, poor understanding of mental illness

People's knowledge of what is good or bad mental health is generally poor, they expect their mind to work in the future as it does now. People accept that they might become depressed, however almost no-one expects to develop severe mental illness. Most people's understanding of mental illness is based on media coverage.

Stage Two:

first experience of mental health problems

The individual, their friends and family usually do not recognise symptoms of mental ill health when they appear. Psychotic symptoms very rarely occur in an instant. They often arise in the context of a steady decline that may be apparent in school performance, interpersonal relations and so on. People find other explanations for changes in behaviour - hormones, school, relationships, etc. but are not able to be specific enough to get appropriate help.

Stage Three:

first experience of mental health services

The symptoms are often described as having "taken over" at this point and the individual is often judged as "not responsible" for their actions. Mental health services' response to "crisis" behaviour is often one that takes away an individual's liberty.



Stage Four:

diagnosis and treatment

Professionals often monitor a person for months before deciding on a diagnosis. People can spend weeks or months in hospital before being discharged to the care of their family and friends. People will often lose contact with friends, education and work, experience discrimination and be excluded from many aspects of community life.

Stage Five:

recovery oriented care and support

A care plan should be provided by mental health services to help the person resume daily life. Carers often feel bewildered, and families have to learn to adapt to the person's needs. The illness and the effects on the other areas of their life may well frustrate the person.

Stage Six:

mental health improves

The person begins to recover, with less need to engage frequently with mental health services. Pressure on the family may subside and carers may begin to see an improvement. The person may feel well enough to structure their day-to-day activities.

Stage Seven:

symptoms return unexpectedly

Many people experience relapse, their symptoms return and their condition worsens to an extent where intervention is necessary. The person becoming unwell again may not recognise their deterioration and, for some, a reoccurrence of stage three may occur involving compulsory treatment and restraint. Once more the person becomes "a patient".

Stage Eight:

further down the road to recovery

With experience of crisis, diagnosis, admission and relapse, the person will be fully aware of the context. They will need to be aware of the part that stress plays in poor mental health and their care plan should help them to adjust, plan for the future, and promote their recovery.

Stage One

Good mental health, poor understanding of mental illness

This is where almost everyone starts from, whoever they are. They have no personal experience of mental illness (generally the symptoms related to schizophrenia, bi-polar disorder and severe depression do not appear before late teens). People's knowledge of what is good or bad mental health is generally very poor and they take for granted that their mind will work in the future as it always has. People tend to think of depression and anxiety as things that could happen to them, but that psychosis could not. The stigma that still surrounds mental illness means that accurate descriptions are rarely seen in the media, in education, at the pub, in faith centres or whilst shopping. Stigmatising attitudes towards people with psychiatric disorders may now be the largest single obstacle to improving their quality of life ⁽¹⁾. Family members, friends, the general public, employers and even doctors may express negative or discriminatory attitudes.

Facts

- 60% of young people admit verbally abusing people with mental illness ⁽²⁾
- 50% of people with mental illness report abuse and harassment ⁽²⁾
- 94% agreed that we have a responsibility to provide the "best possible" care for people with a mental illness ⁽³⁾
- In a recent Mori survey 38% of people aged 18 to 25 were unable to name any form of mental illness⁽⁴⁾
- two thirds of all press and television coverage associated mental illness with violence ⁽⁵⁾

What helps at Stage One?

- Programmes specifically tackling misunderstandings and stigma relating to severe mental illness.
- Combating discrimination against individuals and groups with mental health problems.
- Health improvement programs to promote good mental health: in schools, workplaces, neighbourhoods and the media.
- Promoting social inclusion of people with mental illness.

For details of best practice in this area visit www.rethink.org/reachingpeopleearly

Stage Two

The first experience of mental health problems



Symptoms start to appear. As the individual has no idea of what mental ill health is they do not recognise what is happening. Their friends and family, likewise unaware of the signs, put the changes down to hormones, school, relationships, and the weather, whatever feels "safe", or "understandable". Sometimes the individual knows something is wrong, but not what. When they ask for help, people's ignorance, often including that of primary care services, results in either no help at all or support that is inappropriate. Stigma, fear and denial of being unwell may also make it difficult to seek help.

Facts

- The average wait for treatment, after the onset of clear psychotic symptoms, is between 52 and 78 weeks ⁽⁶⁾
- 39% of adults with a psychotic disorder had not consulted their GP within the last 12 months about their mental health problem ⁽⁷⁾
- Only 42% of GPs are satisfied with the time they spend on mental health matters ⁽⁸⁾

What helps at Stage Two?

- Easy access to help when it is needed e.g. better links between primary care and psychiatric services.
- GPs being ready to make early referral to specialist services for further assessment, treatment and care if required.
- Use of NHS Direct, as it develops, for first-level advice and referral on to specialist help-lines or to local services.
- Training for other services that might encounter people with early onset mental illness e.g. Student Counsellors.
- Additional "gateway" workers in primary care to improve access to mental health services ⁽⁹⁾
- Listening to carers - family and friends are often first to seek help and advice.

For details of best practice in this area visit www.rethink.org/reachingpeopleearly

Stage Three

First experience of mental health services

Eventually something happens that gets a response. The symptoms are often described as having "taken over" at this point and the individual is often judged "not responsible" for their actions. Because of "crisis" behaviour (that might put the individual's or, more rarely, others' physical health at risk) the service response is often to take away the individual's liberty. Restraint, sometimes involving the Police Service, is commonly used, as is detention or compulsory treatment under the Mental Health Act. Sedative medication and a hospital environment, that many people find frightening, ensue.

Facts

- 35% of people with a severe mental illness are turned away when seeking help ⁽¹⁰⁾
- 27% of people who rang NHS Direct, did not feel that the nurse was able to deal with their problem ⁽¹¹⁾
- More than 50% of people's first admission to a psychiatric bed is compulsory i.e. under a section of the Mental Health Act (1983). ⁽¹²⁾
- 13% of posts in general adult psychiatry in England are vacant, and there are 372 Consultant Psychiatrist vacancies in England. ⁽¹³⁾
- Of the 50 early intervention services required by April, 2004 only 16 teams are in place. ⁽¹⁴⁾

What helps at Stage Three?

- Duty doctors, approved under section 12 of the Mental Health Act (1983), and approved social workers always available to respond to mental health emergencies.
- Rapid assessment of the person's need at times of crisis.
- High quality, well staffed acute wards to minimise the trauma of hospital admission.
- Crisis houses, intensive home treatment and crisis resolution services as alternatives to hospital admission.
- Involvement of relatives, partner, friends, etc.

For details of best practice in this area visit www.rethink.org/reachingpeopleearly

Stage Four

Diagnosis and treatment

Professionals often monitor a person for months before deciding on a diagnosis. Older medications, known as typical anti-psychotics, may be used to alleviate symptoms of the underlying illness. Older medications are cheaper but tend to have devastating side effects including muscle tremors, weight gain and limited concentration. Newer medications, known as atypicals, tend to have far fewer side effects. People often lose contact with close friends and peers who may feel uncertain about how to respond. The school, college or workplace may have "lost" contact with the person; and may not be sympathetic about the person returning.

Facts

- 62% of people with a severe mental illness have not been offered a choice of medication. ⁽¹⁵⁾
- Almost 70% of people treated for schizophrenia receive older medications. ⁽¹⁶⁾
- "The value of cognitive therapy in reducing distress arising from psychosis is well established: however, the number of people trained to provide this therapy in the NHS is scandalously low". ⁽¹⁷⁾
- NICE decision (June, 2002) states "The choice of antipsychotic drug should be made jointly by the individual and the clinician responsible for treatment based on an informed discussion of the relative benefits of the drugs and their side effect profiles".

What helps at Stage Four?

- Information available for people with mental health problems, including access to local self-help groups and support services such as housing and employment.
- Care plans for those with a severe mental illness including an urgent follow-up within one week of discharge from hospital.
- Using clinical guidelines, all service users should be assessed for and receive new anti-psychotics or other medication where indicated.
- All people with severe mental illness should have access to Cognitive Behavioural Therapy, or other psychological treatments.

For details of best practice in this area visit www.rethink.org/reachingpeopleearly

Stage Five

Recovery oriented care and support

A care plan should be provided by mental health services to help the person resume daily life. This plan should be orientated toward the person's recovery and build on their strengths not just address weaknesses. The individual should own it - rather than the plan being developed by those professionals involved in the person's support. Carers often feel bewildered and families have to learn to adapt to the person's needs. Siblings may not be fully aware of what has happened or how to help. Parents / Carers do not always know how to explain the illness to other children. The person may be frustrated by their illness.

Facts

- Only 6% of mental health service users knew what a care programme was, and how it was meant to work ⁽¹⁸⁾
- 65% of people do not have a copy of their care plan ⁽¹⁹⁾
- 58% of Trusts do not consult service users about their care plan ⁽²⁰⁾



What helps at Stage Five?

- Comprehensive care planning – with the active involvement and engagement of the user.
- Care planning that anticipates or prevents crises, and reduces risk.
- Occupational support services oriented toward recovering a fulfilling life.
- Support to find and keep suitable housing.
- Access to services 24 hours a day, 365 days a year.
- Monitoring of waiting times for referral to psychological therapies and action implemented to tackle delays.
- Regular monitoring and review of medication, including side effects, with a willingness to change medication to improve outcomes for the individual.
- Regular, programmed, physical health checks.

For details of best practice in this area visit www.rethink.org/reachingpeopleearly

Stage Six

Mental health improves



Feeling well again. There may be less need for contact with services. Carers may begin to see an improvement in the person. Stress on the family may subside, although underlying pressures of caring will still be present. The person may feel well enough to begin structuring their day-to-day activities.

For many people, the involvement of their informal carers, families and friends is integral to all stages of their recovery.

Facts

- 87% of carers (caring for people on CPA) want to be involved in care planning ⁽²¹⁾
- About half Britain's carers haven't been told of their right to an assessment ⁽²²⁾
- The Carers (Recognition and Services) Act, 1995 provides the right to assessment of carer needs and production of a carer's plan
- The Carers and Disabled Children Act, 2000 specifies that the carer's own plan must be taken into consideration when implementing the care plan of the person they care for.
- In addition, some carers will have rights as nearest relatives under the Mental Health Act, 1983.

What helps at Stage Six?

- Additional staff; working for carers and integrated with mental health services.
- Carer Education programmes.
- Health and social services assessment and support for carers

For details of best practice in this area visit www.rethink.org/reachingpeopleearly

Stage Seven

Symptoms return unexpectedly



Some people will relapse. Their condition will worsen to an extent where intervention is necessary. Sometimes the person may realise that something is wrong and either volunteer or be encouraged to accept treatment for their illness. However, the person becoming unwell again may not recognise their deterioration and, for some, a reoccurrence of stage three may occur involving compulsory treatment or restraint. Once more the person becomes "a patient" and will likely feel a loss of control. Understandably, the person may begin to lose hope of ever being well with accompanying frustrations for themselves, carers and siblings. People from black and minority ethnic communities often experience more frequent compulsory admissions, under the Mental Health Act, (1983).

Facts

- 187 "provider defined" assertive outreach teams, of the 230 required by April, 2004, are in place. ⁽²³⁾
- Only 52 crisis teams, of the 335 required by April, 2004, are in place. ⁽²⁴⁾
- 88% of people with severe mental illness, from black and minority ethnic communities have been detained under the Mental Health Act, 1983 at some time in their lives – compared to 42% of "white" respondents. ⁽²⁵⁾

What helps at Stage Seven?

- Intensive home treatment and crisis resolution services.
- Crisis cards, advance directives and other plans agreed by the person with professionals, their family and friends about preferred treatment should they relapse.
- Timely access to an appropriate hospital bed or alternative place (e.g. crisis house): in the least restrictive environment needed, as close to home as possible.
- A copy of a written after care plan that sets out the care and rehabilitation to be provided, identifies the care co-ordinator, and specifies the action to be taken in a crisis.
- Local "specialist services" to anticipate and prevent a crisis using, including early intervention, assertive outreach and rehabilitation.
- Carers of people with severe mental illness should have seen and had explained to them the care plan of the person for whom they provide care; understand the nature of their illness; know how to contact services if they need to.

For details of best practice in this area visit www.rethink.org/reachingpeopleearly

Stage Eight

Further down the road to recovery

When they are feeling better, the person has an opportunity to remain in contact with services. Their care plan should help them to build up life skills and begin to plan for the future. They will need to be aware of the effect that stress has in aggravating mental illness. Recovering a fulfilling life is attainable but requires appropriate support and needs to be nurtured.

Facts

- Only 13% of people with a history of psychiatric disorder are working. ⁽²⁶⁾
- 23% of DDA employment cases are taken by people with mental health problems. ⁽²⁷⁾
- 85% of people with severe mental illness found "physical exercise" and "training" of therapeutic benefit. ⁽²⁸⁾
- It is completely unacceptable that up to one third of people being treated in inpatient units throughout the country are simply in the wrong place. ⁽²⁹⁾

What helps at Stage Eight?

- Recovery oriented support.
- Training and support for self-management.
- "Hearing Voices" groups, etc.
- An holistic approach to needs including: rehabilitation; accommodation: access to education and training and occupational and social support
- Use of Disability Discrimination Act (1995) to enforce rights to employment and reduce discrimination against people with severe mental illness ⁽³⁰⁾

For details of best practice in this area visit www.rethink.org/reachingpeopleearly



Campaign and Research Objectives

This report launches Rethink's "Reaching People Early" Campaign.

Our objectives are to:

- Raise awareness amongst the public of the benefits of seeking help early.
- Give people easy and direct access to help and information.
- Work in partnership with the statutory and voluntary sectors to ensure consistent responses.
- Campaign vigorously for additional resources to reduce the length of time between symptoms appearing and receiving help.
- Develop new services and service models that respond to today's mental health needs.

To achieve this, we will:

- Undertake research to discover the experiences of people with severe mental illness and their families of their first years of living with a severe mental illness.
- Produce and disseminate materials for the general public and work in partnership with organisations such as the Institute of Psychiatry to increase our understanding of effective mental health promotion.
- Work closely with primary care providers to meet their needs and promote good practice such as the IRIS Guidelines on early intervention.
- Continue to develop effective services and support for people with severe mental illness and their families.

The Reaching People Early Campaign is part of Rethink's wider campaign work lobbying for:

- Reaching people early.
- Informed choice/best fit medications.
- Evidence based talking treatments.
- Recovery oriented social support.
- Continuous and responsive care management.
- Carer involvement, support & education.
- All delivered with respect, choice and involvement.



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Rethink severe mental illness is the new operating name for NSF, the National Schizophrenia Fellowship. Working together to help everyone affected by severe mental illness, including schizophrenia, to recover a better quality of life through:

- reaching people early;
- helping people affected to recover a meaningful and fulfilling life;
- supporting the people who are most disabled;
- changing attitudes and tackling discrimination.

Rethink is a campaigning membership charity involving people with severe mental illness and carers, with a network of mutual support groups around the country. Rethink is also the largest voluntary sector service provider in mental health, helping 7,500 people each day.

Institute of Psychiatry

IoP carry out research in psychiatry, psychology, and allied disciplines: including basic and clinical neurosciences. The Institute is world renowned for the quality of its research. The Institute works with the South London and Maudsley NHS Trust.

Initiative to Reduce the Impact of Schizophrenia

IRIS has a belief in the importance of effective early intervention for young people with psychosis. These organisations collaborate in the development and promotion of services specifically focused on the needs of young people with psychosis and their families.

To participate in this campaign, or other Rethink work contact us at:

rethink severe mental illness

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Visit the Rethink website at www.rethink.org

You can find a copy of this report at

www.rethink.org/reachingpeopleearly

Registered Charity Number 271028

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IRIS www.iris-initiative.org.uk

IoP www.iop.kcl.ac.uk/IoP/home.stm



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