

About Rethink

Rethink, the leading national mental health membership charity, works to help everyone affected by a mental health condition recover a better quality of life. We provide hope and empowerment through delivering effective services and support to all those who need us, and campaign for better mental health care provision through greater awareness and understanding.

To continue our work and build on what we have already achieved, we depend on your support. Please visit **www.rethink.org** to find out more.



Contents

Introduction	4
Study method and participants 5	
Recovery insights	6
Acceptance	9
Control	12
Interdependence	16
Learning points for recovery For people experiencing mental	19
health problems	19
For friends and family	21
For mental health professionals	22
Reflections on doing research	1 25
Additional information	32
References	38

Throughout the report pseudonyms are used to protect the anonymity of participants. For reasons of confidentiality the testimonials used sometimes do not relate to the individuals photographed.

Foreword

Rethink's mission is to support everyone affected by severe mental illness to recover a better quality of life. We strive to do this in the delivery of frontline mental health services, through campaigning and our membership activities. Any organisation is constantly reflecting on its practice and the recovery narratives programme, led by the Rethink research team, has provided us with information, presentations and training to question current practice and skill up staff to work in new ways.

I have been at several events where the seven researchers with personal experience of mental illness on this project have talked about recovery, this project and what they want to see happen in mental health services in the future.

The research provides a very powerful base from which to make informed suggestions that challenge existing practices and suggest helpful ways of taking the recovery agenda forward.

To really facilitate shared decision-making in health and social care, we all need more insight into what it feels like to have a mental health condition and to take steps towards recovery. This involves understanding the 'whole person' – not just the symptoms, but people's personal aspirations, their social situation and the wider context of their lives. We hope this booklet makes a useful contribution.

This publication, and the study it is based on, was made possible by AstraZeneca who kindly provided a sponsorship grant towards this work. The Rethink research team has had full independence and control over the design, data collection, analysis and write-up of findings.



Paul JenkinsRethink's Chief Executive

Introduction

This report is about the different ways in which people live with and recover from persistent or recurring mental health problems. It draws on 55 people's personal experience of mental illness and psychiatric treatment.

This study is based within the tradition of 'personal recovery' research (Andresen et al. 2003, Slade 2009). Drawing on the accounts of people who have experienced mental health problems, we describe what helped or hindered their recovery.

We hope that the report will be relevant to many people affected by severe mental illness. We provide findings and practical suggestions for people who feel overwhelmed by mental health problems and are struggling to believe that recovery is possible for them. They may also provide hope, inspiration and encouragement to people to make best use of individual

circumstances and opportunities to work towards personal goals. We hope the report will be equally useful to people in supportive and caring roles.

In order to protect their anonymity, the names of participants given in this report are pseudonyms.

The full research report

Getting back into the

world: reflections on lived
experiences of recovery can
be downloaded from
www.rethink.org/intotheworld

"Recovery is about building a meaningful and satisfying life, as defined by the person themselves, whether or not there are ongoing or recurring symptoms or problems." Shepherd, Boardman and Slade 2008

Study method and participants

Seven people with personal experience of mental illness and psychiatric treatment worked as researchers on this project. They conducted semi-structured interviews with 48 people in order to gain a deep understanding of people's beliefs, attitudes and lives in relation to recovery. A particular quality of this study was the researchers' use of personal experience throughout the research. A detailed account of the methods can be found in the full report (Ajayi et al. 2009).

The same research team wrote this short report, deciding which findings should be prioritised and what learning could be drawn out for different readers. The Rethink research and communication teams provided editorial assistance.



The research participants

The 48 interviewees were selfselected and recruited through mental health networks across England.

Participants were from 23 to 74 years old, with the largest group being aged 45-54 (33%). They were equally from both genders (54% female). The majority described themselves as White British (90%). All had considerable experience living with mental health problems – they had their first episode of mental illness between 11 and 34 years ago.

The most frequently reported diagnosis was bipolar (43%), followed by anxiety (36%), depression (36%) and schizophrenia (21%). Several participants had been given more than one psychiatric diagnosis during their time in mental health services. Prior to the interview, participants were asked to selfrate their 'wellness' on a scale from 1 to 10 (1 being unwell and 10 representing very well). Most people rated themselves as feeling relatively well at the time (an average of 6.8).

Recovery insights

Ten key themes were developed in the data. These themes represent different aspects of people's lives that could play a part in their experience of mental health recovery. They fall into two groups: contextual themes, that concern the person's situation or environment, and personal themes, that concern personal awareness, identity and understanding.

Contextual themes

- Basic and material needs:
 Recovery crucially depends on issues such as settled accommodation, financial security, basic human rights and being a citizen.
- Stigma and isolation: Prevailing societal perceptions and attitudes impact on the person in recovery. Stigma can block recovery and reinforce isolation.
- 3. Relationships: Positive relationships within which the person feels supported and encouraged are essential to build confidence to move forward. The challenge for people in recovery is to distance themselves from negative relationships, while building and nurturing supportive relationships.

- 4. Receiving support: People need support when unwell.

 Mental health professionals should take a human approach, and engage with people. Mutual and informal support networks can play a critical role in maintaining recovery.
- 5. Treatments: Psychiatric hospital is often a negative experience for the person, although some feel that it may be necessary at the time. Medication may for many be an essential part of their treatment, but one that should not stand alone. It is important that the person is given informed choice over the type and dosage of medication that is right for them. Talking treatments, like counselling or psychotherapy, are valued by many and should be offered to everyone.

Personal themes

- 6. Identity and self-awareness:
 Recovery involves developing greater self-awareness and confidence in one's own identity.
 This involves understanding the illness and developing relationships and social roles to support personal growth.
- 7. Taking responsibility: It is important for people to take an active role to engage in their own recovery. This can be frightening: finding the necessary motivation and courage depends on personal motivation and adequate support.
- 8. Self-management and resilience: The person in recovery needs to develop knowledge of personal 'triggers' to illness. Much can be learned from others with similar experiences, but both triggers and coping strategies are very individual. Living through longer periods of wellness builds resilience and confidence in recovery.

- 9. Having a purpose and belonging: Being recognised by others and being involved in something bigger are essential. However, too much pressure to achieve particular aims can have a negative effect. It is important to find roles and challenges that are appropriate to each individual.
- 10. Spirituality and cultural wisdom: For some, various spiritual practices and beliefs are a source of comfort and help put the mind at rest. People may seek spiritual help in different ways, but mental health professionals rarely offer support.

These ten themes are similar to findings from other research on what is important in recovery (Brown and Kandirikirira 2007, Davidson 2003, Andresen et al. 2003).

However, our analysis brought out a new perspective highlighting how these themes interrelate in peoples' lives, when they confront choices that are potentially life-changing.

Recovery mediators of contextual and personal themes

Basic and material needs Stigma and isolation Relationships Control Receiving support Treatments Personal themes Self awareness and identity Self management and resilience Taking responsibility Having a purpose and belonging Spirituality and cultural wisdom

During the analysis the research team identified three additional 'recovery mediators':

- Acceptance
- Control
- Interdependence

These three factors wove their way through people's stories, often linking the personal and contextual aspects. It seemed that they had to be confronted and grappled with if progress towards recovery was to be sustained.

Throughout the following description, the ten recovery themes have been picked out in bold as we trace the paths of the three recovery mediators. We have included quotations and case stories from interviews to illustrate the significance of the recovery mediators in people's lives.

Acceptance

Acceptance has a powerful role to play in recovery. Interviewees talked about the importance of being accepted by others and how this helped them to come to terms with their mental health problems.

Learning to accept themselves, their illness and the difficulties they faced was often a key precursor to recovery. Acceptance can lead to changes in lifestyle, attitudes and expectations, a growth in **self-awareness** and beginning to adopt or accept a new **sense of identity**.

"I just accept that this is the way I am, and once you've accepted it, then you can work with it."

Woman, 35-44 years old

Acceptance by others, especially family and friends, promotes a sense of belonging. However, stigma can lead to rejection, isolation, and a negative self-image. The acceptance and support offered by others with similar experiences can be crucial as people re-enter the social world.

"Living in a community, in a way, of like-minded people who know what it's all about and not being afraid to tell those who you hope you can trust and to be brave enough to say that 'well, if they didn't understand then so be it', rather than to be crushed by lack of understanding – which is what happened to me for so many years."

Woman, 55-64 years old

Feeling accepted has an impact on self-confidence and wellbeing. Being accepted as part of a bigger picture allows people to develop a sense of purpose and feel it is possible to contribute to society. Some people found a route to acceptance and a sense of belonging through spirituality or religious beliefs. Practising 'mindfulness' or meditation may enable people to stay in the present, and avoid anxiety about the future or the past.



Terry's story

Terry, one of the researchers, has lived with paranoid schizophrenia for 12 years. This is his story:

For me, acceptance was the 'pass go' stage in my recovery journey – the first crucial step leading to real progress. It involved admitting to myself that I do have a mental health problem and I need help. I wasted 6 years in the beginning by denying my problems and crashing around like a freight train before finally coming to terms with it.

When someone confronts you with the line 'you're ill' it's easy to reject it out of hand and dismiss it totally. But denial can be extremely damaging. I see my first 6 years in the system as being in limbo. Acceptance of my illness was a turning point – the start of my path to wellness.

It is important to understand that denial of the illness can be a natural reaction and a normal defence mechanism to a very painful truth. Society has a dim view of mental illness and the stigma around it is very powerful. For me, denial was my way of coping, of staying normal. It was a way of dealing with the initial trauma of breaking down.

The trouble with not accepting is that you also reject treatment. You refuse medication, fight confinement and rebel, or worse – turn on those trying to help you. This behaviour gets you nowhere, and just makes things worse. By accepting treatment I could actively seek the right medication, access support, and turn my life around. Without acceptance you remain trapped in the delusion that nothing's wrong. I've seen many stuck there – a bad place to be.

I had no idea how to get here in the bus and I began panicking on the bus. But I brought myself into the moment and I said, 'well, you're not there now, you're not doing that now, this is where you are now'. Woman, 65-74 years old

Many research participants talked about how **relationships** could be both helpful and unhelpful at different times and in different ways. Relationships where there was acceptance, mutual understanding and empathy were most supportive of recovery. However, relationships can raise

the possibility of being controlled and dependent, and reinforce rejection or isolation. Friendships with others who use mental health services could provide empathy, understanding of symptoms and non-judgmental **support**:

I love talking to other people... I've really learnt from meeting people with different diagnoses that we're all the same. All that's different is what we do, and how extreme we get. But I finally understand the symptoms and that's all due to your life and your life experiences.

Woman, 35-44 years old

Beth's story

For Beth, feeling accepted by others and being treated with kindness – as a human being – was a turning point in her recovery. For many years she had been hearing aggressive voices and often felt terrified and suicidal. Beth was constantly told that she was 'a bad person'. On occasions she had used violence, towards herself and others, as a way to cope.

Things started to change when she became involved in a project for people with mental health problems. There, staff believed what she said about herself and her problems. Beth was not used to this. She felt accepted. Staff helped her realise that her extreme moods didn't mean she was a freak, and that she had a choice about how to behave. She was responsible for her behaviour and could change it.

Beth has been helped to realise that anxiety was part of her character and that she could manage it. There are other things that she would like to change about herself in future: 'Recovery is accepting that your mental health is actually a part, a necessary part, of your life'.

© Rethink 2010 www.rethink.org

Control

People's experience of regaining power and control over their lives was another key aspect of recovery, which wound its way through the ten recovery themes. The mental health system can feel – and often is – immensely powerful, and disempowering to the people using it.

Some of those who experience severe and acute mental health problems do lose control over their lives, albeit temporarily. Some level of control must be reclaimed for recovery to be effective and long-lasting.

"I can become dependent like a baby in four hours in a psychiatric setting. So that can do damage. So you have to be able to receive what is useful and to discard what is damaging."

Man, 55-64 years old

One of the ways in which some people had learnt to take some control over their lives was through the use of **self-management** techniques. Self-management refers to organising one's life to maximise health and avoid unhealthy behaviours or things. It is often an important part of the

recovery process. In order to self-manage, it is necessary to develop **self-awareness**, especially of one's mental health, potential 'triggers' of illness and factors that aid recovery. Participants described self-management strategies that involved gaining more control over their own situation. Other strategies involved disengaging from unhealthy practices or situations.

"The other thing that has helped me is 'disengaging' from the psychotic behaviour or psychotic feelings. So, if I hear voices or see something strange, I don't engage in it. I think it's a conscious choice. You can either engage in it, which can get you in a spiral of elation or, if you want to keep an even keel, I don't engage in it."

Man, 35-44 years old

Alan's story

Alan talked about his experiences of mental illness after having an episode at work in a high-powered job. He experienced severe bullying from his work colleagues and believes it happened because some people in the work place liked to use what he called the 'whipping stick' to exert and enforce their power over others. Consequently Alan had a serious mental breakdown.

Eventually he received the help he needed. He described how he felt very 'calmed' and reassured by the authorities when they stepped in to treat him. Alan saw this as a turning point in his recovery journey. In contrast, he found dealing with his parents less helpful: 'they became a bit disruptive and overpowering. They wanted to control everything by thinking: "you are our son and we want you to get better". He wasn't happy with this change in their relationship and now keeps them at arm's length, so that he can keep control of things himself.

After learning about assertiveness, Alan felt he had greater control over how people treated him. He believes that his own passivity may have contributed to his work colleagues turning on him – it drew out their negative behaviour. By asserting himself he believes he can stop naturally aggressive and domineering people from trying to control him. Using assertiveness techniques has enabled Alan to take 'a more even place in society'.



Mary's story

Mary was thrown into severe depression following her father's suicide. The response of the mental health system led her to experience total loss of control: 'I was strapped up by the ankles and the knees with handcuffs on the wrists, tied up by the elbows and thrown in the back of a paddy wagon.'

Since then Mary has fortunately been able to gain a greater sense of influence over her treatment, for example in discussions about medication with her social worker and GP. Both agreed with her that she had been receiving a stronger dose than she needed at the time. Mary described how they have decided together to lower the dose, and 'meddled with how much I was to have morning and night'. Now she works with them as a team, and so gains greater control, whilst seeking approval for the changes she hopes for.

She manages to work with different professionals to reach decisions concerning her treatment that she agrees with, even when some professionals might disagree: 'I did try and ask my psychiatrist and do it properly, but he refused to see me, so we just did it without him.'

Mary now feels very much in control of her life as she sets herself new goals. 'I've been stable now for nine months... it's a great achievement, I'm aiming to hit twelve months.'



Some people had attended courses, such as psychoeducational or self-management. Often, the value of these lay in learning from others who had similar experiences. People's coping strategies may be very different, as this woman learnt:

"If you get a group of people all together and you can all see the commonality of, like, the symptoms [...] one guy saying he starts listening to, like, any disco when he's getting high. And another guy saying: 'oh, I cook loads of pancakes'."

Woman, 18-25 years old

Some people found that taking personal responsibility for their medication enabled them to feel more in control of their lives, when previously it had seemed that the medication symbolised a lack of control. Experiencing side effects often made people feel powerless. However, support and understanding from professionals, including being offered a choice of different medication, enabled them to regain some sense of control.

"The weight gain was terrible, it was really bad... I do a lot of exercise now, I run 3 or 4 times a week just to get the weight off... I would have been a lot happier if, when they put me on [medication] they also put me on some sort of exercise machine or physical support to counteract the weight gain."

Woman, 45-54 years old

Some found empowerment through relationships with other people: the support of others could strengthen their confidence and self-esteem. Sometimes gaining a degree of distance from their family enabled people to regain a sense of being in control. Many found talking treatments helpful in enabling them to take control over their lives and their illness, giving them a greater understanding, a new perspective or new skills.

"I've just had some psychotherapy for three years, and I really feel that it has helped a lot and it's been quite a profound experience. It's almost like a festering wound that hadn't been really healed over properly. So, by looking at it and talking about it and coming to terms with it is almost that ... the stuff has come out of the wound and it's being allowed to heal."

Woman, 35-44 years old

© Rethink 2010 www.rethink.org 15

Interdependence

The theme of interdependence highlights once again the crucial role of **relationships** in recovery. When unwell, people often find themselves in a position of enforced dependency, both on services and on friends and family. When well, people may feel driven, or pushed, towards a kind of artificial independence which can result in **isolation**.

Our study suggests that recovery means finding a balance – or a 'third way' – between dependency and independence: a level of interdependence with services and other people, which will vary according to the specific situation or relationship.

"However much my friends had helped me, to some extent, they were actually holding me back... they'd got into the habit of treating me as ill, but expecting more from me despite that."

Man, 45-54 years old

The difficulty is that breaking out from a position of dependency depends on each individual relationship, and the willingness of both parties to allow the relationship to change. Taking greater control over one's own treatment can be a way in which the relationship with mental health professionals can move from dependency towards interdependence. An interviewee described a point early in her recovery when she felt profoundly dependent upon her support worker:

"I was asked to escort this lady that was going to the computer class but she found it really difficult to get out... I thought: 'oh god, I can't do that ... Anyway, I supported her to get to the class and I felt so good that I... I didn't feel as I could support myself and it just made me feel that, you know, that I had something to offer." Woman, 45-54 years old

At first she felt incapable of doing this, and somewhat horrified to be asked. Looking back, she saw this as a turning point; she is now involved in many supportive activities. Having a purpose through helping others can be an important way for people to develop a new role in relationships; they can feel empowered by giving to others. Peer and self-help groups can be important vehicles for this, as can voluntary or community engagement activities.

Margaret's story

In recent years Margaret has been proactive in developing supportive relationships involving some of her good friends and her daughter: 'What I've actually tried to do is build a circle around myself'. She and a good friend who has similar mental health problems looked up warning signs to get a better understanding of what to look out for if a crisis were to occur. She shared this information with her network: 'I've talked to them a lot about what bipolar is, what the signs are, what to look out for, what to do so warning signs should be picked up and it should never get to that point.'

Margaret has come to recognise the importance of her wellbeing to other people, as well as the important role other people can play to maintain her wellbeing. Only recently her daughter prevented an escalation in her condition: 'she's got a really good relationship with my CPN [Community Psychiatric Nurse] and she phoned my CPN and said, you know, "there's something wrong with mum, this is not right".' Good communication between the family and mental health professionals was in this case essential.



16 www.rethink.org © Rethink 2010



Tyron's story

Tyron lives in his own flat and described his main problems as isolation and boredom. He felt he had out-grown the local Mind drop-in centre. He has been struggling with mental health difficulties and feels his diagnosis of schizophrenia is wrong. However, he has found reading medical books and keeping a journal useful in making sense of his experiences.

Tyron used phrases like 'blossom where you're planted', or 'count your blessings'. He also expressed the desire to be a good person, saying 'I don't drink or smoke.' These sayings and aspirations appeared to be deeply rooted in his family and his African Caribbean culture.

Not getting much help from his relatives in England, Tyron has had to be dependent for money and support from his mother in Jamaica. However, he said: 'I've done my best to be independent' which he feels is an important part of his recovery. At the same time he appreciated the support from mental health professionals and described his psychiatrist as being 'like a father to me'. He added: 'Everybody and everything can play a part in your life... Everything is interrelated.'

Learning points for recovery

Our interviews, reflections on the data and discussions in the research team have illuminated learning points which are relevant to different groups. All have important roles to play in shaping and encouraging, or hindering and discouraging the recovery of people living with mental health problems.

For people experiencing mental health problems

Recovery has a different meaning to each person. We hope some of the suggestions below may be useful to you in your recovery. You may already be doing some or all of these things. Perhaps some don't feel right just now. Each person has their own route to recovery.



- 1. Acceptance: Consider the possibility that some level of acceptance may come first on your road to recovery. Denial of your problems or of parts of yourself can be damaging.
- 2. Identity: You do not have to feel boxed in or labelled by diagnoses or by what others think of you; you have the right to re-define and re-name your problems for yourself in your own language. This can often help in reclaiming your identity.
- 3. Self-management: There are many different strategies and techniques that people find helpful; it is important to remember that it is unlikely that one technique will fit all. We encourage you to find out what works for you. Do not to be discouraged by early disappointments.

© Rethink 2010 www.rethink.org

- 4. Peer support: Finding support from others who have similar experiences or diagnoses can be very valuable. We encourage you to find out if there are any local support or self-help groups in your area. (See suggested list at the end of this report.)
- 5. Talking treatments: Many people have found it helpful to have a professional to talk to about their mental distress. We encourage you to try some form of talking treatment, such as counselling, psychotherapy or cognitive behavioural therapy (CBT).
- 6. Spirituality: Consider and value your own spiritual needs whether that for you is through religion, meditation or creativity or something different.

 These can help you gain self-awareness and peace of mind.
- 7. Recovery: Whether you consider yourself to be 'in recovery' or recovered, we encourage you to keep using the techniques of self-management which work for you. Being aware of how you are feeling and the things that may have a negative effect on you can help you anticipate and tackle potential problems. Good mental health can never be taken for granted.



For friends and family

These points emerge from the research – you may feel you are doing all of these, or those that feel appropriate right now.

We hope to provide useful suggestions about how friends and family members can help to support recovery, and how you can make sure that you value yourself and care for your own health.

- 1. Acceptance: As you accept the mental health problem, do not forget the person. Continue to value their views and opinions and do not see all that they do or say as a symptom of illness. Do what you can to show your love and support. You do not need to know all of the details about their diagnosis or behaviour to do this.
- 2. Education: Learn about the illness or diagnosis, how it feels to experience such mental health problems and ways you and others can offer support. (See sources of information at the end of this report.)
- Mediator: You can play a vital role in mediating between the service user and mental health staff, or acting as advocate on

- their behalf. Offer to accompany them to appointments. Your support can make a big difference to the outcome.
- 4. Regaining independence is a vital part of recovery: Try to encourage your friend or relative a with a mental health problem to go out, to join a support or self-help group, and to do things independently. Be patient, however people need to move at their own pace, rather than to fulfil others' expectations.
- 5. Interdependence: It is important to help an individual to find a balance between independence and dependency. Both extremes of can be harmful; independence can lead to isolation, while dependency can lead to people taking on a 'sick role'.
- 6. Remember the fun things in life: Going out and doing ordinary things together can make all the difference to a person's recovery.
- 7. Your needs: Think of your own mental health needs, seek support for yourself. If you are experiencing stress, it is difficult to help someone else. Take a break when you need it.

For mental health professionals

These points emerge from the research. You may feel that you already do all of these, but it's always worth remembering some of the basics when building recoveryoriented relationships.

- 1. When someone first becomes unwell: First experiences are so very important in a person's life and future recovery: explain clearly what is happening, reassure the person and their family. People can hear and absorb things no matter how ill they appear to be. They are probably very frightened.
- 2. Put yourself into the shoes of the person with mental health problems. Ask 'what would I need if it was me?' We are all human beings with feelings and needs, strengths and weaknesses.
- 3. Engage with people, talk to people, listen to what they have to say. If you are honest with people when they are vulnerable or unwell, you are more likely to establish a relationship with them that is based on trust. Relationships of trust and support are vital in supporting recovery.

- 4. Trust that a person knows themselves very well listen to and respect what they have to say. The helping relationship needs to be a collaborative one, to which both of you bring your knowledge, experience and expertise. Do not assume they don't know what they are talking about because they have mental health issues. This can be very disempowering, and is sometimes dangerous.
- 5. Don't let procedure get in the way of humanity. It is your humanity that will help someone's recovery, not blindly following procedures that can at times de-humanise both of you. Remember the reason why you chose to do this job. Prioritise the relationship, not the paperwork.
- 6. Look and think beyond the diagnosis: Remember that each person is an individual human being. Many of us have had different diagnoses at different times, and have learnt to regard them with some scepticism. Others have found a diagnosis to be an important step on the road to recovery. Either way, a diagnosis is not what defines an individual.



7. Take a holistic approach to all support and treatment, an approach that is not just based on medication, particularly for people in hospital.

Talking therapies can help someone in crisis, and a range of alternative interventions (e.g. getting involved in art, sport or gardening) can help as well. 8. Find ways of helping people towards empowerment.

People have lost control over their minds and their lives; they often feel completely disempowered and that they have no choices. Any opportunities that you can find for people to start to regain control (often in small ways), to have choices and to take initiatives will help them towards recovery.

- 9. Engaging and encouraging people to help others can empower them. This can help them to feel that they have something to offer and that they have a purpose in relation to other people.
- 10. Build a positive relationship with family and friends. Involve and inform family and friends appropriately. Listen to their concerns. Remember that often they are the ones who provide the daily support which can help establish lasting recovery.
- 11. Be open to talking about or listening to people's spiritual or religious beliefs: Having spiritual concerns responded to, rather than dismissed, can be extremely significant in the recovery of some individuals. People are often discouraged from talking about these issues. If you do not feel equipped to talk about spiritual concerns, training and support may be available or it may be more appropriate to refer them to someone else. (See sources of information at the end of this report.)
- 12. Don't dismiss people's beliefs however unusual they appear to be at first. Often they are based on something important and real to the

- person expressing them. They may be an important route to understanding that person.
- 13. Remember that the consequences of being in hospital can be damaging for people. Treating people well, with care and respect, and offering hope at this time of crisis will help them to recover and reenter the world more easily.
- 14. Information about treatments, medication, side effects and services can empower people by giving them the possibility of informed choice. Find out what resources are available locally (from both voluntary and statutory organisations) and help people by offering them information and signposting. At the start offer answers to questions asked, rather than giving too much information.
- 15. Peer support can be a powerful tool in a person's recovery: The isolation that often accompanies mental illness can be disarmed by meeting others in similar situations. Find out what opportunities exist locally, signpost people to local support or self-help groups, or help to set up a group yourself within the service where you work.



Reflections on doing research

Seven people with personal experience of mental illness and psychiatric treatment were recruited as researchers. Training in research methods was delivered by a mental health survivor research consultant, Alison Faulkner, and support during data collection and analysis was provided by the Rethink research team.

The researchers here reflect on their experiences of taking part in the study, from the design of the interview guide to the analysis, write-up and dissemination of findings. Two of the researchers have decided to remain anonymous, a testimony to the stigma of mental illness that unfortunately still pervades our society.

24 www.rethink.org © Rethink 2010



Alice

I was very pleased to be invited to join this research project, as I am passionately

interested in recovery. How people manage to recover in so many creative and courageous ways is truly inspiring. I have learnt many new skills along the way; being part of a team of other researchers with lived experience was very reassuring and stimulating. Using the reflections of my own experiences was very interesting, making me feel I had some specialist knowledge.

It was a great privilege to hear people's recovery stories. I often

felt very moved by what people were telling me and sometimes even picked up some tips as to how to manage my own mental health problems. Sometimes I did follow lines of enquiry that resonated with my experience. However, I was always mindful of the person whose interview it was and was able to be sensitive to the subjects which were of importance to them. Many of the people I interviewed told me how good it was to be interviewed by someone 'like them'. They felt on an equal level with me and were able to say things that they had never expressed before.

This has been an exciting and sometimes challenging year for me: another big step in my own recovery journey. I am sure our published results will prove to be of great value to others on their recovery journeys.

Anonymous 1

Taking part in this study has been a truly worthwhile experience. Firstly, it has given me the chance to use my skills, something which is really important to me, and secondly, it has allowed me to turn around the negative experience of mental illness and put it to good use to help others.

We worked together tremendously well as a team. I got to know my Rethink colleagues at a far deeper level than anywhere else I have ever worked. On my first evening out with them, for example, Roger asked me, "What are your mental health triggers?" Questions such as this helped me to think about my own mental health in a different light. This not only

helped with the project but also with my own recovery. Working on this project has made me realise that I can do something to help others and my goal in life is to continue to use my experiences of mental illness for the benefit of others.

Anonymous 2

Taking part in the study has meant a great deal to me on a personal and professional level. I found interviewing incredibly interesting and a privilege to hear people's very personal stories. I appreciated the openness of the participants. Perhaps because of our personal experience of mental distress, interviewees talked openly without fear of judgement.

When I listened to interviewees' responses and related them to my experience it deepened my understanding of my own mental distress and recovery. It helped me to stand back from my experiences and make sense of them. Professionally, involvement in this research study had led to more research opportunities and work. I've also appreciated learning research skills. Being involved with all stages of the study, designing the research tool, interviewing and analysis, writing up the report and dissemination has been a fantastic learning opportunity.

Peter

In the beginning, I found it quite daunting but it was also such a



good team. When people made comments during the interviews, it touched memories of my past, from their experiences and my own. Everybody's experiences are different. I found the interviewees were telling different stories as to how people get on the road to recovery.

Travelling to different places on my own, which I hadn't done before, meant I was gaining confidence. Nerves were bad while I was travelling but I settled down when I got there. It proved I could do it! I found it a big help and looked forward to our meeting together. As a team we were relaxed and friendly.

I am sad it's coming to an end but I am sure the team will keep in touch. We have all made friends with each other, which is reassuring for us.



Roger

A few days after the interview to join the Rethink team I wrote, "My mood has improved as this was my first successful interview in 14 years". I felt I had a good understanding of recovery and was surprised to find my ideas so challenged as I listened to others' views. Prior to the project I had little time for people with my diagnosis who claimed to

be 'recovered'. I had been 'in-recovery' for 10 years and believed I would always be 'in-recovery'.

The interview process put me in a situation where I was listening carefully to people who had formed their own ideas through a wide variety of experiences. I came to accept that a phrase like 'inrecovery' will never fit everyone. I now see myself as having been through a period of recovery and am now in a period of relative stability. I can say I have moved beyond recovery whilst accepting that what I learned when in recovery must not be forgotten. Good mental health is something I will never take for granted.

Ruth

I enjoyed the initial training when we worked on the interview schedule. This included interviewing each other about our personal 'recoveries', which developed trust and enabled us to get to know each other quite deeply and very quickly. We also practised interviewing with friends between our team meetings, gaining useful feedback. This gave me a good understanding of how the interview could 'feel'

to the interviewee, and added depth and perspective to my interviews.

After this I was confident that I could interview more effectively. I could draw on my own experience (internally) to empathise and understand more deeply during the interview. I could recognise and cope with my own emotional responses during the interview, for instance when the interviewee's experiences resembled my own,

or reminded me of my past. I felt privileged to hear other people's stories - they were always interesting and often moving.

The team lived in far flung parts of the country, so our meetings to analyse the data and write up findings were quite short and often became very intense. We all held our own ideas about some of the core issues, which led to heated debates. However, we also used our reflective diaries through the project to consider its impact on ourselves. I found this a useful way to reflect on my feelings and learn. Altogether, being involved in this project helped me re-consider my own experiences of illness and recovery.



Terry

I see my involvement in the research project as one of the best experiences I have had since becoming unwell over a decade ago. It has been tremendously therapeutic to be able to share my negative and painful mental health experiences with others to aid the greater good. I really enjoyed the innovative method of the study which allowed us to

use our personal knowledge to help guide and 'interact' with every stage of the project. Our 'reflexive' input was used from start to finish and for me this gives our study a high level of validity.

Being involved in this study represents for me a major stepping stone in my recovery journey. Everyone needs to feel needed and useful; being a researcher has opened doors for a possible career or employment which were firmly shut before. On a very personal level it has increased my sense of purpose and self-esteem. I have a new found respect for myself and have met some really interesting and inspiring people who have helped me move forward in my life. Before this study I was full of despair but now my outlook is much more hopeful, having seen what can be achieved when like-minded people get together and work so well.

Suggestions for others carrying out similar work

After the project we reflected on what might have been helpful to us during the research process:

- 1. Payment must reward people's work appropriately. While there was clarity on how many hours would be paid for different aspects of the work, people at times worked additional hours as a voluntary contribution. A great deal of time was spent travelling; some felt there should be payment for this. Clarity and transparency about rights to claim expenses (e.g. for subsistence) is vital from the outset.
- 2. Effective facilitation of meetings is important to let everyone participate and contribute fully. While it was good for the whole team to discuss some issues all together, splitting into pairs or smaller working groups was at times more productive.
- 3. Full time research managers working with part time user researchers should be mindful that user colleagues may not work normal office hours. They need to give good notice when setting **deadlines**. This enables user researchers to manage their time and health successfully.

- 4. Managers could consider whether user researchers have skills to undertake other tasks that would otherwise be outsourced – like the transcribing of interviews.
- 5. Research managers should demonstrate confidence in people's 'life skills'. One said 'the Rethink management were exceptionally good; just that at times, they seemed to lack confidence in our life skills, such as booking trains. It is a fine line between providing support to workers with mental health problems whilst appreciating that much of the time they are as capable as anyone.'
- 6. Despite the collaborative approach to working together, some felt that the Rethink researchers were 'the boss' and made the significant decisions. A way to address this would be for user researchers to take direct responsibility for generating research ideas, project funding and management.

- 7. Being involved in research can improve mental health but can also cause stress (e.g. dreading panic attacks; addressing one's own painful memories from the past). Role play during training can help people prepare for difficult situations.
- 8. Decisions regarding the confidentiality of service user researchers must be addressed carefully and clearly; for example, what it means to be named in conference presentations and publications. Some may want to protect their anonymity; others welcome being publicly recognised for their work.
- 9. At times of difficulty, service user researchers did not always feel able to approach the Rethink research managers for additional support. Opportunities for regular individual supervision meetings would have been helpful. The ideal mentor/supervisor would be an experienced service user researcher rather than the line manager.





Additional information

We recommend you to seek additional information and support to assist the journey towards recovery. It can sometimes be difficult to know where to look and who to approach, but there is a variety of information and resources available.

The Rethink Advice and Information Service (RAIS) produces factsheets with practical advice and information on a range of issues relating to mental illness. Below we have presented some of these under the headings of themes identified in our research. You can find and download the RAIS factsheets free on this website www.mentalhealthshop.org

Basic and material needs

RAIS factsheets

- Housing Options Explores
 accommodation options available
 to people with mental illness
 and how you might access the
 housing you feel you need.
- Debt and Mental Illness –
 Explains how to deal with debt and manage finances.
- Employment Support Allowance

 Provides information about the main benefit received by people who cannot work because of illness. This factsheet explains how to apply.
- Disability Living Allowance This is paid to cover costs which may result from a disability including mental illness. This factsheet explains how to apply.
- Revisions and Appeals Many people have problems accessing the benefits they are entitled to. This factsheet explains how you can appeal decisions not to grant certain benefits.

Useful links

Shelter – This is the leading housing charity in the UK. They offer advice and help on all aspects of housing, including homelessness and poor housing through their online advice service and 24 hour freephone telephone line, Shelterline. They can also direct you towards local housing organisations in your area.

Shelterline: 0808 800 444 www.shelter.org.uk

National Debtline – Provides free, independent, confidential advice on a self-help basis.

Tel: 0808 808 4000 www.nationaldebtline.co.uk

Consumer Credit Counselling Service – Offers free, confidential advice and support to anyone worried about debt.

Tel: 0800 138 1111 www.cccs.co.uk

Citizens Advice Bureau – Helps people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers. They can help to check you are claiming the correct benefit and help to challenge any unfavourable decisions.

www.citizensadvice.org.uk

Stigma and discrimination

RAIS factsheet

Disability Discrimination Act –
 Explains how the law can protect you from discrimination due to mental illness.

Useful links

The Disability Law Service – Provides confidential and free legal advice for disabled adults, their families and carers; and can provide a casework service.

Tel: 020 7791 9800 www.dls.org.uk

Skill – Provides information and support for students, colleges and universities, and can advise you on your rights under the Disability Discrimination Act.

Tel: 0800 328 5050 www.skill.org.uk

Receiving support

Advocates can be useful in helping you get the care and support you feel you need. They can help arrange Care Programme Approach assessments as well as attend meetings with you to help.

Useful link

Action For Advocacy – Can help you find an advocate in your area. www.actionforadvocacy.org.uk

Treatments

RAIS factsheets

- Talking Treatment Explains different kinds of psychological therapy and how you can access them.
- Care Programme Approach –
 Many people with severe mental
 illness receive their care package
 under the Care Programme
 Approach and this factsheet
 provides detailed information
 about what you can expect from it.
- Only the Best A guide to antipsychotic and mood stabiliser medication including how they work, what the benefits and side effects are and what to do if you disagree with your medication.
- Second opinions Explains how to go about getting a second opinion either for a review of your diagnosis or treatment
- Complementary therapies Many people find that non-mainstream approaches can be beneficial as a complement to their treatment.
 This factsheet explains the main complementary therapies and how to access them.

Useful links

UK Council of Psychotherapy

 Holds the national register of psychotherapists and psychotherapeutic counsellors.
 Here you can find therapists in your area.

Tel: 0207 014 99 55 www.psychotherapy.org.uk

British Association for Counselling & Psychotherapy

 Is the main body in the UK representing counselling.
 www.bacp.co.uk

The Maudsley Psychosis
Outpatient Unit – Provides
specialist assessments for
medication and treatment on
referral.

The Complementary Therapists
Association – Represents
complementary therapists in the
UK and Ireland. On their website
you can find out about the different
complementary therapies as well
as find a therapist.
www.ctha.com

Self-management and resilience

RAIS factsheets

- Coping With Hearing Voices brings together different self management approaches which can be useful for people hearing voices.
- Self-management Rethink report describing people's own approach to managing their illness which fellow service users and professionals can learn and benefit from.

Useful links

MDF the Bipolar organisation – User-led charity working to enable people affected by manic depression to take control of their lives.

Tel: 08456 340 540 www.mdf.org.uk

The Hearing Voices Network -

Works to reduce the isolation of people who hear voices. Provides support and self-help groups across the country. Has produced the publication Coping with Voices and Visions. Information

Tel: 08451 228 641 Helpline: 08451 228 642 www.hearing-voices.org

Having a purpose and belonging

RAIS factsheets

Work and Mental Illness –
 Explores different options
 available to people to get back
 to work after mental illness
 and as well some of the main
 barriers people face and how to
 overcome them.

Useful links

Do-it – Enables interested volunteers to be matched with local organisations looking for help.

www.do-it.org.uk

Skill – Promotes opportunities for young people and adults with any kind of impairment in post-16 education, training and employment.

Tel: 0800 328 5050 www.skill.org.uk

Spirituality and cultural wisdom

RAIS factsheet

 Spirituality – Looks at the role spirituality may play in the life of a person with mental illness how you can get your spirituality needs met.

Useful links

Buddhist

Amida Trust – Based around the Buddhist principles of compassion and a psychology mode based in Buddhist understanding of the mind.

Tel: 0116 286 7476, www.amidatrust.com

Christian

Association for Pastoral Care in Mental Health – A Christian foundation providing training, support and other services for people with a mental illness and their carers.

Tel: 01483 538936 www.pastoral.org.uk

Christian Counsellors Directory

 Produces a loose-leaf directory listing Christian organisation and individuals in the UK who offer various forms of counselling.

Tel: 01903 761818 www.graceministries.org.uk

Acorn Christian Foundation -

Seeks to demonstrate that Christian healing is a sound companion to modern medicine and offers a spectrum of services to church and society, groups and individuals.

Tel: 01420 478121 www.acornchristian.org

Islamic

The Muslim Women's Helpline -

Provides any Muslim girl or woman in a crisis with a free, confidential listening service and referral to Islamic consultants, plus practical help and information where required.

Tel: 020 8904 8193 or 020 8908 6715 www.mwhl.org

An-Nisa Society – An inclusive organisation working for the welfare of Muslim families.

Tel: 020 8902 0100

Union of Muslim Families -

Offers one-to-one advice and support to families. Advice on health problems and advice and support in domestic and marriage problems.

Tel: 020 7226 0934

Jewish

Chizuk – For strictly Orthodox Jewish men and women with mental health problems. Offers drop-in with separate sessions for men and women, a home befriending service, hospital visiting, adult placement service and access to hostel accommodation and advocacy.

Tel: 020 8800 7494 Email: info@chizuk.org.uk severe mental illness and their carers.

Tel: 020 8371 7319

www.mentalhealth-jami.org.uk

Jewish Care – Offers an extensiv

Jewish Association for the

Mentally III (JAMI) - Provides

advice for people suffering from

guidance, support, counselling and

Jewish Care – Offers an extensive network of services for people who are experiencing emotional difficulties and distress or coping with severe or enduring mental health problems. This includes residential facilities, rehabilitation centres, employment and training initiatives and mental health outreach work.

Tel: 020 8922 2000 www.jewishcare.org

The MIYAD Crisis Helpline -

Provides anonymous help, advice and comfort for Jewish individuals in crisis.

Tel: 020 8203 6211 or 0345 581999

Mindfulness

Centre for Mindfulness Research and Practice – Based at Bangor University the Centre offers training programmes and lists professionals delivering mindfulness-based interventions.

Tel: 01248 382939 www.bangor.ac.uk/mindfulness

References

Ajayi, S., T. Bowyer, A. Hicks, J. Larsen, P. Mailey, R. Sayers, R. Smith and two anonymous authors (2009). *Getting back into the world: reflections on lived experiences of recovery.* London: Rethink. www.rethink.org/intotheworld

Andresen. R., L. Oades, P. Caputi (2003). *The experience of recovery from schizophrenia: towards an empirically validated stage model*. Australian and New Zealand Journal of Psychiatry 37:586-594.

Brown, W. and Kandirikirira, N. (2007). *Recovering mental health in Scotland. Report on narrative investigation of mental health recovery.* Glasgow: Scottish Recovery Network.

Davidson, L. (2003). *Living Outside Mental Illness: Qualitative Studies of Recovery in Schizophrenia*. New York: New York University.

Shepherd, G., J. Boardman, M. Slade (2008). *Making recovery a reality*. Sainsbury Centre for Mental Health: London.

Slade, M. (2009). 100 ways to support recovery: a guide for mental health professionals. London: Rethink. www.rethink.org/100ways



Join us

Rethink works tirelessly to improve the lives of those affected by severe mental illness. If we are going to continue to succeed we'll need your help. You can support us in any number of ways for example becoming a member, making a donation or becoming a campaigner.

Please support us today to help transform the lives of generations to come. To find out how you can help visit www.rethink.org, phone 0845 456 0455 or email info@rethink.org

Information on mental health

For more information about Rethink publications and other products on mental health, please visit www.mentalhealthshop.org or call 0845 456 0455.

Make a donation

We cannot achieve our goals without the vital funds donated by supporters. Donate today by calling 0845 456 0455 or donate online www.rethink.org

Acknowledgements

This booklet has been funded by AstraZeneca

38 www.rethink.org © Rethink 20



AstraZeneca has provided a sponsorship grant towards this independent programme

"Recovery is longevity in wellness."

Research participant

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

A copy of this report is free to download from www.rethink.org/recoveryinsights

Authors

Terry Bowyer, Alice Hicks, Peter Mailey, Ruth Sayers, Roger Smith, Sarah Ajayi, Alison Faulkner, John Larsen and two anonymous authors

For further information on Rethink Phone 0845 456 0455 Email info@rethink.org www.rethink.org



Printed on 100% recycled paper

RET0468

Registered in England Number 1227970
Registered Charity Number 271028
Registered Office 89 Albert Embankment, London SE1 7TP
Rethink is the operating name of National Schizophrenia
Fellowship, a company limited by guarantee
@ Rethink 2010







