



# Reality of Crisis

The experience of having a mental health  
crisis and of accessing the Crisis  
Resolution and Home Treatment Teams

A collaborative, qualitative service user led research study

conducted by AMaze  
(the Service user and carer research group)

And academics, clinicians and research supporters (East  
Midlands MHRN and Research Consultant)

**'Reality of Crisis'**  
by  
the AMaze research team  
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(inspired by some of the themes emerging from the research)  
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# ‘Through a Glass Darkly’

1 Corinthians 13:12

Dedicated to the memory of Gregory James.  
A good friend and a key research member who during this project  
sadly passed away April 2009

*“Your dedication in the hardest of times,  
your humour that lightened our load  
it helped us when we struggled  
and inspired us to carry on”*

## **Authors' Preface**

### **Why 'Through a Glass Darkly'?**

The subtitle looking 'Through a Glass Darkly' has been chosen for this report because we felt it summed up what we have been trying to do throughout this challenging research project [and finding a non-depressing title which we all liked and which related to crisis was proving difficult!]

Conducting research is like looking at an object through a piece of glass (as if through the lens of a telescope). Sometimes it is focused sharply on one specific area and at other times our view is spread more widely; taking in a larger perspective but with less detail. The glass often appears misted and can itself distort the image we are exploring. Good research tries to limit these distortions and make the glass clearer. In developing this project, we were lucky: we had a head start because the rich mix of people in the research team helped us understand the broader issues from a service management to a service user level. Interviewing people who had recently gone through a serious mental health crisis allowed us to clear away more and more of that mist in order to gain a better understanding of what was really happening in their lives during that difficult time.

This report collates our findings from all those service user conducted interviews and gives a clearer picture of the Crisis Resolution and Home Treatment Teams from the perspective of people who have used them. This unique research perspective can be combined with other conventional pieces of research in order to gain a fuller understanding of what works and what does not. The reasons for success or failure became more apparent as people shared their experiences with an interviewer they could trust. Most importantly, changes to the services can now be instituted based on these findings and we hope that, in time, it will lead to better quality services for people in an acute mental health crisis. Not surprisingly, many of the things people need when they are in a crisis are not based on 'rocket science' but rest in the everyday attributes of the world around us.

For the sake of brevity, we have shortened the term Crisis Resolution and Home Treatment Team to CRHT. We have also used the term 'Service User' to describe people who use the mental health services. We recognise that not everyone would agree on a single term and we had to arrive at a practical consensus in order to write this report. Some of us would have preferred to be known by our own names as individuals who have, at times, accessed the mental health services but this would have been impractical especially when there are others who would prefer to remain anonymous.

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# Introduction

## Current Crisis Provision - Why this Research Project?

### **Brief outline of the research project and rationale for the study**

In 1999, the National Service Framework identified the need for 24 hour crisis provision. Before the implementation of the Crisis Resolution and Home Treatment Teams, there was very little access to mental health services outside of usual working hours. In the East Midlands, out of hours help was only available through the Accident and Emergency departments and the Social Services' out of hours duty system. Also, there was no opportunity, when experiencing a crisis, to receive treatment at home. Hospital admission was the only option if there was a serious risk to oneself or others. Many voluntary organisations plugged the gap by setting up out of hours help lines but these were usually limited in scope. Therefore, the UK Government set out to form 365 Crisis Resolution and Home Treatment Teams in England and Wales by December 2004. On the basis of research elsewhere, it was hoped that bed usage would be reduced and that with mental health workers assisting people in their own homes, the cause of the crisis might be tackled: thus reducing the recovery time needed and minimizing further crises whilst still maintaining the individual's independence and control over their own care.

Crisis Resolution and Home Treatment Teams are designed to deliver two functions. The first is to offer rapid access for assessment of someone thought to be experiencing a mental health crisis (within 4 hours). The Home Treatment part of the service subsequently provides time limited, intensive home treatment and support.

In essence, the Crisis Resolution and Home Treatment Teams provide crisis support and treatment at home for those going through a mental health crisis and are accessible 24 hours a day, 7 days a week. As indicated above, they were introduced to help reduce unnecessary admissions to hospital and to provide support near the onset of a crisis in order to minimise the need to access long term mental health provision. Since their introduction, there have been mixed anecdotal reports on what it is like to use the service and on the effectiveness of these new teams; some reports being negative and others positive. It is not clear which outcome is the more prevalent or representative. We wanted to find out from the people who were accessing the services what their experience was like, did it help, in what way, and if not, what from their point of view, could be done to make things better? Of the negative anecdotal reports, we wanted to discover whether this was more universal than some believe or were just related to teething problems when the teams were first introduced.

Most published research has examined in detail the impact on statistical performance such as bed usage and has evaluated the teams from a conventional health service perspective. We concluded that we should look further into what was working well and what required

improvement from the perspective of those who were accessing the service. We had wanted to include the carers'/families'/friends' experiences in this research project, but due to the limits of time and funding we could not feasibly do this. Nonetheless, we believe that carers' views are equally important and consider that it is an area of research which we would like to see carried out in the future

This is a qualitative study analyzing transcripts from interviews conducted across the whole of Nottinghamshire and Lincolnshire with people who used those services over a 2 week census period in September 2007. We assembled a varied team of researchers including people who use services, their carers, academics, clinicians and research staff and conducted 36 interviews with people who had recently used one of these teams. It is important to acknowledge that many members of the Research Team have personally used the mental health crisis services in the past. This report highlights the methods used and the findings from that study. A briefer handout of the results is also available.



# Aims

## **Research themes from an insider perspective:**

- How does the experience of Service Users affect their perception of CRHT input?
- What is the experience of the journey people take when experiencing a mental health crisis?
- What helps and what hinders recovery from a mental health crisis?

## **Involvement**

From the onset, we wanted to encourage involvement from a wide range of people with a variety of experiences and skills. This included the CRHT Teams/ service users/ carers/ academics/ clinicians/ research staff/ and managers. We felt that not only would this bring a diverse range of experiences, abilities and skills to the research team but would also reflect, as far as possible, differing viewpoints. Maintaining that involvement throughout the project was vital. Doing so proved difficult and challenging. We worked through these problems by being open with each other in discussion, and feel that for the most part, we have been successful in our goal. Practical difficulties were a major hurdle which we could not have overcome without the support of the Mental Health Research Network in the East Midlands Hub and many of the other Research Team members. One outcome was assured: we have all grown significantly and learnt from the experience of working with each other.

## **Method Used**

We conducted 36 semi-structured interviews across Nottinghamshire and Lincolnshire covering all nine Crisis Resolution and Home Treatment Teams. We used a 2 week census period in which we identified all the people who accessed the teams during this time. They were all given information about the study and invited to express an interest in being interviewed.

The domains covered and questions used in the interviews were chosen by conducting a number of focus groups, the majority of which included mental health service users and carers.

## **Training**

Advertisements were widely disseminated and invited anyone who used mental health services (as well as carers) to become involved in the research project. If interested, they were requested to attend a series of training days to learn more about the study and be trained in conducting interviews. The draft set of questions was piloted during this training exercise and amendments were made in light of the responses.

Training was delivered in both Nottingham and Sleaford with around 20 people attending.

## **Interviews**

Each interview was carried out by 2 trained interviewers, one of whom was always a mental health service user and the other either a service user or carer. We had procedures in place to help support all those who took part. Interviews took place in people's own homes or at a neutral venue such as a Community Hall. A demographics questionnaire was used to ensure that there was an equal spread of interviewees across the Crisis Resolution and Home Treatment Teams in the East Midlands and which was stratified for age and gender.

## **Transcription**

All the interviews were taped and notes were taken during the interviews. The tapes were then transcribed and identifiable information removed. The transcripts were subsequently analysed.

## **Analysis**

Two lots of analysis were undertaken, one set by a qualified Social Scientist, and the other by Amaze. The Amaze team was drawn from the interviewing group of service users and the carers who went on to undertake the analysis. Their personal experiences of using the services of Crisis intervention teams gave them a unique perspective as Insider Researchers.

Both pieces of analysis were conducted blind to each other but the themes and findings were very similar. The analysis from the Amaze Group was more extensive although similar themes arose when the results were triangulated by the research team.

## **Insider Research Technique**

The Methodology underpinning the research was phenomenological in nature because this approach focuses on how life is experienced and on the ways in which people interpret and make sense of their personal experiences.

The danger of this approach was the risk of over-identification with other service users in similar positions. There was the real possibility of projecting meanings onto those interviews that were not actually shared by respondents. The method employed to counter this was Reflexivity. Individually and collectively, the interviewers reflected on their own personal experiences of situations similar to the ones described by the interviewees. In this way, they were able to acknowledge and identify the differences within the categories of data between the interviewee experiences and those of the researchers. When conducting Insider Research, reflexivity is an essential tool used both to recognise the researchers' personal experience and the impact the research content exerted on them. Our experience of using the services helped us analyse more deeply the content of the transcripts. Also, it helped us comprehend what interviewees said in a more appropriate way. At times, this was distressing for us not least because the content sometimes challenged our own beliefs and experiences. Keeping Reflective Diaries throughout the research project helped us address this issue and because we were working as a group we could reflect on our shared experiences together. We have been pleasantly surprised by the outcomes of the research (which, of course, is how it should be).

When we looked at the transcripts we realised quickly that we were seeing dynamic stories of the individual's journey from the very onset of a mental health crisis, through to recovery (rather than a static cross sectional view of events). This could have been the consequence of the way we had posed our questions but also because the process of narrating a journey appeared to come more easily to many of the participants.

# A Unique Research Approach

What makes this project unique is the determination to combine a rigorous scientific approach with that of Insider and Action research methods. This project involved collaboration between service users, carer, clinicians, academics and research supporters. Our understandings of the realities of mental illness varied according to our differing roles. The following offers a perspective of this range of positions:

'We construct our realities at the interface between the experience of our senses, our ability to think and our capacity to believe. Our emotions and moods colour these realities, also giving additional meaning to our lives. This takes place between people and in social situations. It includes those who may vary in the way they construct their realities and perceive those of others.' (Collier, 2010).

Service User led research may run the danger of over-involvement and over-identification leading to a lack of critical judgement. There is always an element of being an outsider in all those undertaking insider research whether or not this is recognised by the person concerned. It's identification and employment in the research process is crucial for the validity of the undertaking.

If undertaken on a teamwork basis, the establishment of common ground between researchers over approach needs to be continually worked on. The honest identification and acceptance of agreed areas of difference can be part of this common ground.

A self-questioning attitude to the research approach throughout the life of the project is a necessary safeguard to avoid the 'heffalump traps' that await the unwary researcher!

It is the common ground reached from these varied approaches that enable effective collaboration to take place. This takes time and is the outcome of a process (sometimes difficult) of learning to communicate and mutually understand one another. Other methods having a bearing on the research undertaking included aspects of Grounded Theory and Action Research.

Grounded Theory was used with a view to maintaining an open mind and not approaching the analysis of data in a preordained way. The raw data was coded and categorised. The categories emerged both from the researchers' scrutiny of the data available to them and the ways in which they themselves were already categorizing and making sense of the world.

Action Research came in as a 'given' – the project was set up to supply evidence that could lead to change and development of services in the community for people experiencing acute mental distress. In the cyclical structure of Action Research, the stage we are just entering now is stage 4 (in the first round) out of 5.

# Insider Research

## Benefits and drawbacks

### A Definition of Insider Research

Insider Research is undertaken by an individual or group who wish to explore an aspect of the world in which they form a significant part. In our case, the service user and carer researchers all used or looked after someone using the NHS Mental Health Services.

The general characteristics of Insider Research are broadly phenomenological in nature. The researchers shared numerous experiences which allowed them to establish a good rapport with interviewees. The researchers used a creative approach which is concerned with description and interpretation, action and process, rather than analysis, measurement and structure, and in general prefer qualitative methodology but equally are able to accommodate quantitative elements.

### Benefits

We have all maintained a Researcher's Reflective Journal which is an essential part of any qualitative research. This has not only helped monitor the impact the research exerted on us and recorded the ups and downs of the process but it has also enabled us to recognise the unique benefits of being an Insider Researcher.

Three examples highlight some of these benefits:

1. Unfortunately we were unable to use two interview transcripts. One because of a technical hitch with a recording machine and another due to the information being distorted as a consequence of the presence of a carer during the interview. We felt that although the Service User had answered some of the questions, we recognised on listening to the tape that she/he could not answer freely with their Carer present. The Carer, although well meaning, had answered a lot of the questions directly.

As Insider Researchers we have direct experience and personal knowledge of the Mental Health Services and as a result we were aware that Service Users and Carers can and often will have a different perspective of mental health distress and treatment. We considered whether a researcher who had no insider knowledge would have accepted the interview transcript as it was because they might not have recognised how important these different perspectives could influence the research outcomes. Although we have always recognised that Carers' views of the services are just as essential as those of the Service User, we concluded that the focus of this study was the Service User's experience; not the Carer's. Therefore we did not include this transcript as it was important to us that all Service Users were able to speak freely and fully for our analysis to be valid.

None the less, we feel it will be important to look at the Carer's perspective of the crisis provision in a separate piece of research. To do this effectively we would need more Carer researchers.

2. The questions we asked during the interviews would have been very different if we, the researchers, had not also been recipients of the service. We have used everyday common language in the questions (avoiding jargon wherever possible) and explained and clarified terms used, e.g. Advance Directives, CRHT – Crisis Resolution Team, see **Jargon Buster** at the end of the report.

The style of the questions was chosen to help enable the interviewee explore and describe their journey through their crisis without any time restrictions. We recorded the interview so that we could capture all that was said in order to ensure that the interview flowed naturally and without restriction. We chose this interview method (rather than a semi-structured rating scale) because we knew we would receive better quality information and that the process would be easier for the interviewee.

All Service User/Carer interviewers knew how important it was to make the interviewee feel at ease and to explain their background i.e. that they were themselves a Service User or Carer with direct experience of using services and of having a mental health crisis but who also were trained professionally as researchers.

During some of the interviews, the interviewees became emotional but all of the interviewers were trained to recognise when it was appropriate to take a break and how to cope with the interviewee's distress. Would other professional interviewers who had not experienced a mental health crisis recognise early signs of distress or have handled the situation appropriately or in a different way?

3. Dissemination leading to positive changes.  
The reason we all wanted to undertake this research was because we wanted to bring about positive changes in mental health crisis service provision. We wanted to identify and highlight areas of good practice as well as recognising the areas that need improvement. We wanted to see positive change based on evidence so that mental health teams and services could incorporate our findings in order to improve their service for the people who access them. In our view, insider research gives a sincere and meaningful impetus to this objective

## **Drawbacks**

For us it can be emotionally draining. As interviewers, we all heard what was said first hand and later examined the transcripts. We could relate closely to the experiences of the people being interviewed. We could empathise with the depth of the emotions expressed by people, and understand their frustration when trying to access an appropriate service that would meet their needs.

There were times when we had to finish an analysis meeting early due to the content of the transcript. On those occasions we had to take extra time out to reflect together on the content and how we were feeling. We always knew our role would be difficult and that the experiences of the interviewees would be emotionally draining for us. We were able to overcome these difficulties by talking with each other, by keeping a Reflective Diary, and by constantly bringing to mind the reason we were doing this study in the first place. We wanted to make a difference and, by capturing the interviewee's account of what they had been through, we aimed to reflect their experience in this report.

Personal ill health has also been a drawback at times. Several of us have been mentally and physically unwell during the project and had to take a couple of breaks. However, we found that these breaks gave us more energy when we returned to the work.

# Crisis: Perceived as a journey

As we looked at the interview transcripts, it became apparent that the people we interviewed found it easier to explain their experiences as a process similar to a journey, beginning with the triggers which caused the onset of their crisis followed by their access to the mental health services and other forms of support. Throughout the experience of their journey and when describing it later to the researchers, all interviewees learned a great deal about themselves and readily identified what helped and what hindered their wellbeing and recovery.

## Whose crisis is this?

### **Definition of crisis**

Who defines when a crisis is a crisis? Should this be the crisis team worker, family member, friend or the person going through the crisis?

We found that when CRHT workers evaluated the level of crisis as low, this was reflected in interviewees' perception of the service and support offered in the following way:

- no or little help received
- sometimes not enough
- support given that was not helpful
- frustration of the person in crisis

### **This finding poses a number of questions:**

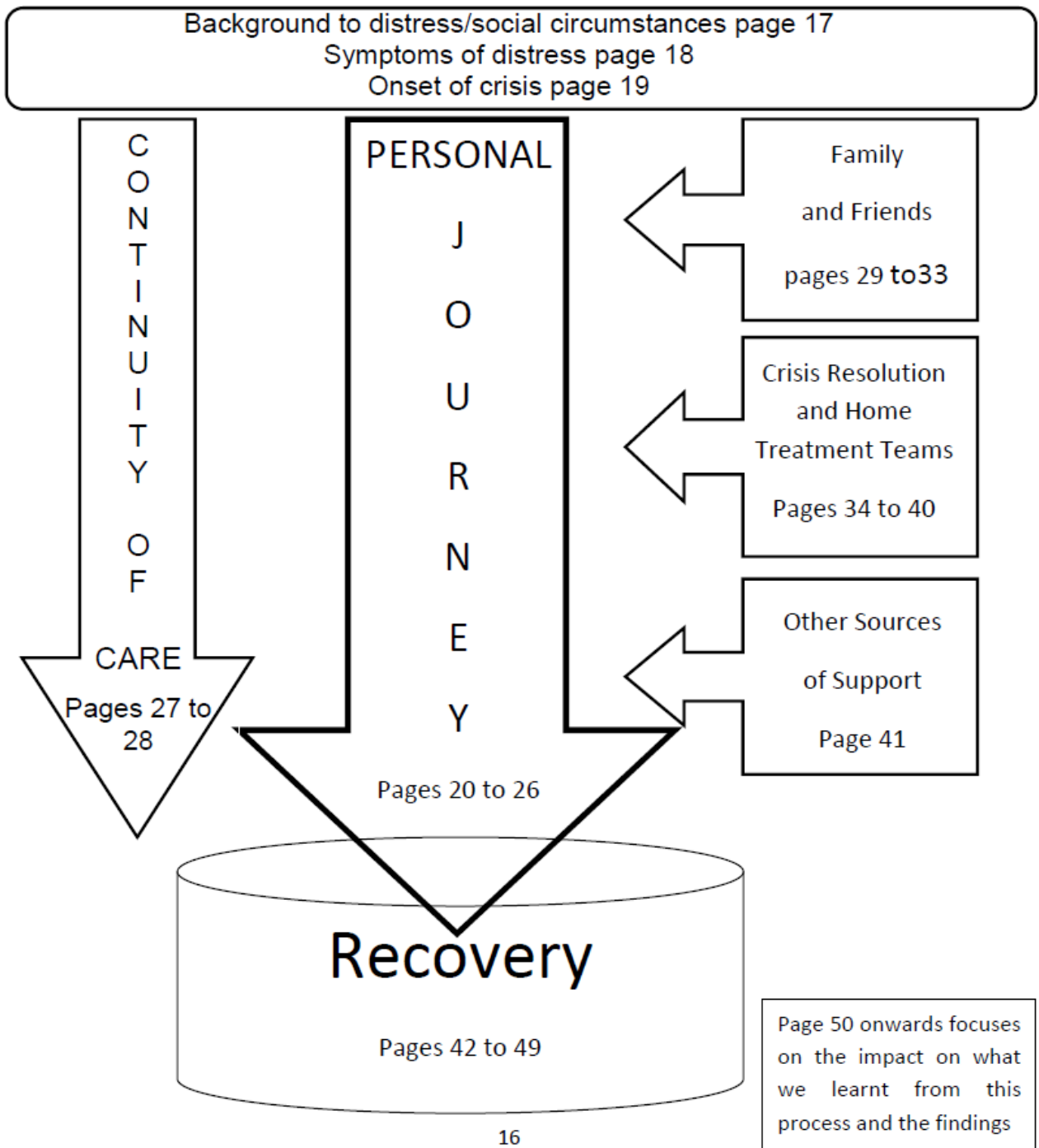
Little things to one person can mean far more to another. Similarly, a crisis for one may not seem like a crisis to another. Experiences can be deceptive. Should a worker wait until someone is a danger to themselves or others before providing support? Alternatively could a CRHT worker prevent the early signs of a relapse turning into a crisis by providing support simply when someone is asking for it?

Many of the people we interviewed had asked for help well before they had become acutely unwell and often were waiting for an assessment by a Community Mental Health Team. Some had received assistance early on, their concerns heard and were supported in ways they knew would help them. For them, the crisis was shorter and they recovered more fully, needing less long term support after the event apart from that offered by their GP.



# Mapping the journey

*A helpful guide to find your way through the results*



# Background to Distress - the Social Circumstances

## **Influence of Family and Friends and Other Sources**

The social circumstances experienced by Service Users were very relevant to their mental illness. Family relationships had a direct bearing on their difficulties. Supportive family and friends could be extremely helpful. However there were many situations when help was not available from these sources.

One Service User who had supported a spouse with mental health problems and a son with a drug addiction felt she had no time or space for her own problems.

Those Service Users who suffered a partnership break-up often felt the most extreme loneliness.

Workplace bullying and harassment were often a cause of stress particularly where it led to a loss of a job. Being out of work resulted in a stressful environment and joblessness sometimes led to the repossession of the Service User's house which added significantly to their existing problems.

One Service User who began a University course found relationships with other students difficult and consequently joined a Manic Depression Group. However this did not help as the lack of positive role models lead to disappointment especially as it did not prove possible to develop friendships there. Suicides in the group greatly distressed the Service User.

Another Service User's illness was seriously affected by having very noisy neighbours which caused him great stress over a long period.

However a beneficial source of support for some was when the Service User belonged to a Church. One person had suffered a number of bereavements in a short time and was helped by a circle of church members who gave appropriate but non-intrusive support.

# Symptoms of Distress

The symptoms of distress felt by Service Users were many and varied. Most people expressed feeling very isolated and 'down', as well as tired and with a desire to stay in bed with the curtains closed. Sleeplessness and not eating were common, together with constant weeping. Many said they felt totally 'stressed', with no interest in anything. They suffered poor concentration with an inability to organise anything in their daily life. Frequently, Service Users expressed feelings of constant nervousness, anxiety, restlessness and worthlessness. Everything seemed pointless. Some overdosed on anti-depressants and paracetamol whilst others resorted to alcohol to dull their pain. Self-harm was common. Panic attacks were also quite common as well as palpitations, delusions, hearing voices and manic behaviour with extreme mood swings. Relationships with partners and family were often strained. Some people experienced physical pain including aches and skin rashes.

Some quotes:

- *'It really wears you down living in that cycle of depression all the time.'*
- *'I just didn't want to have existed at all, just wanted to be completely not there anymore, so I didn't have to feel anything.'*
- *'I felt as if there had been an explosion in my head , it was as if my brain had almost exploded and gone into overdrive ---- when there's been an explosion all bits of dust and dirt and debris fly up into the air and eventually it all comes down to earth.'*
- *'It's like a dark abyss and you just can't do anything.'*  
*'---- it was like a vortex, it was just spiralling out of control so fast. The days were never ending.'*

# Onset of Crisis

The beginning of a crisis could be just as severe as the level of distress experienced at any point subsequently. Feeling totally out of control, panic attacks and relationship problems with spouse, partner or offspring, often indicated the onset of crisis. Difficulties in sleeping, feelings of hopelessness, suicidal thoughts, extreme nervousness and mood swings were also typical. Stress at work, poor concentration, perceived harassment from work colleagues and even the side effects of anti-depressants (which left one Service User feeling muddled and confused), all took their toll. Sometimes, past emotional issues which had not been dealt with at the time, returned to exacerbate matters. For example, because of problems with her husband and son, one Service User had not allowed herself time to grieve over the death of her parent. Consequently, she became completely overwhelmed by her feelings of grief which she described as: *'though I'm having to climb a brick wall every day --- to get somewhere. It's hard.'*

Another Service User described experiencing a feeling of *'overwhelming doom and disaster.'* She burst into tears frequently and found it difficult to function.

# Personal Journey through crisis

Service Users described to us how their journey through a crisis had started, their initial way of coping, the new coping strategies they developed and what they had learned along the way. Some of the interviewees were very perceptive and readily identified what helped them and what had hindered their recovery. Indeed, possessing this level of self-awareness seemed to be the key for helping many of them to recover, to manage ongoing symptoms and avoid relapse.

## Personal Self-awareness

During the journey through their illness and recovery, Service Users gained much self-knowledge. Many acknowledged the need to stay positive, the belief that life is worth living and that it would be possible for them to find the strength to carry on. They realised that although there is often an impatience to recover, it is not always good to rush things and that it can take time to get to the root of problems. However there came a time when they recognised that there was nothing more to be gained from going over the same issues, there was a time to move forward and that the individual could help him/herself. One Service User realised that her suicidal feelings subsided when she talked to someone about them *'it peaks and then it sort of passes.'* Another discovered that he had been suffering from previous post-traumatic stress that had never been properly acknowledged and which was likely to have been the underlying cause of his depression.

Many Service Users became aware of the signs leading to illness and developed strategies to avert onset. One person realised that there were occasions when he was alone that he began to think negatively. He tried to analyse the reasons behind the thoughts in order to *'try to get to the bottom of why I'm thinking like that.'* He is aware that to help himself, he needed to be distracted by undertaking an activity such as physical exercise or throwing himself into a work project.

Recognising feelings of anger, acknowledging their source and accepting that previously he saw things in *'black and white'* helped one person to improve his personal comprehension of what was wrong. Consequently, he was able to develop strategies to deal with these feelings. Recognising symptoms of illness and where necessary to get assistance quickly could help him avoid serious relapse.

Another person was aware that although she had made a lot of progress and that the worst was over, she still needed to work on her recovery and there was much more to do:

*'I think that the black clouds are sort of behind me at the moment and I know that they're there. If I feel that they're coming over me, it's a sort of continuous relationship at the moment, until I feel that my sky is blue, they're there, so it's on going.'*

## **Unhelpful Personal Strategies for dealing with distress**

The interviewees highlighted personal unhelpful strategies they had used. These were mostly at the beginning of their journey before they had learnt other coping styles.

Many Service Users described how their initial coping strategy was to withdraw completely from the world by staying in bed and crying. They lost interest in a basic daily routine, neglected to eat and drink regularly or healthily, and wanted no contact with other people. Some overdosed on medication either as a cry for help or from suicidal feelings. A descent into a chaotic lifestyle of alcohol abuse, cannabis use, a lack of daily routine and mixing with people who encouraged these responses, was a frequent characteristic of Service Users' coping strategy. One person who was on medication drank heavily. The alcohol reacted badly with his medication and he entered into a 'cycle of self-loathing.' Another replaced her medication with cannabis, thinking it would help her to relax and improve her sleep.

There was more than one case where someone in an early stage of recovery tried to do too much too soon and consequently suffered an early relapse. For example, this happened when a Service User became impatient with the speed of her recovery, in addition to feeling worried about how other people perceived her. Some Service Users self-harmed as a means of coping with their feelings. Another, joined a Lithium Support Group but on reflection realised that for her to be surrounded by people who could feel suicidal was not actually beneficial.

## **Types of strategies that people felt hindered their own recovery**

When they:

- tried to return too quickly to the life they had led before the onset of illness and then felt ashamed of and impatient with themselves when it took longer
- worried about everything
- spent a lot of time ruminating about previous negative events which slowed recovery
- abused alcohol , smoked cannabis, overdosed on drugs, self-harmed through cutting and burning due to self-hatred, or did not eat as part of a coping strategy
- stopped heavy drinking too quickly
- let things 'build up' and developed paranoid thoughts
- lacked the confidence to speak out about feelings
- failed to seek help quickly
- lacked knowledge and understanding about mental health distress
- were reluctant to acknowledge that there was a problem at all
- were not getting out of bed each day, or returned to bed during the day, or failed to get dressed and go out each day
- felt they had to listen to lots of questions from others and pressured to make decisions when not feeling well enough to do this
- pushed themselves too hard rather than allowing body and mind to heal
- worried about what people were thinking of them
- cut other people off and shut them out
- had an initial fear of asking for and accepting help
- delayed admitting that something was wrong
- were reluctant to ask for and to accept help for fear of wasting people's time
- were dwelling on upsetting family issues, feeling resentment, and not being able to forgive
- stopped medication suddenly

## Personal Helpful Strategies for dealing with distress

Discovering what allowed them to feel better by identifying the causes, the onset, the triggers and other related experiences helped Service Users progress from an enduring crisis towards a path of recovery. It was a process of personal learning both for the interviewees and their families.

Interviewees went on to describe the helpful coping strategies that they had either already used or developed along their journey. Identifying what didn't help them was perceived as a positive step and many were happy to change the ways they had coped previously. For example, instead of drinking alcohol which one Service User gradually realized depressed his mood, he began to go for walks, met friends and undertook practical tasks.

There was a range of strategies that were found to be helpful. Setting daily targets and establishing a routine such as getting up and dressed, cooking and eating a meal, forcing oneself to go out to the shops, visiting and talking to friends and spending time with the children were all beneficial. Some Service Users were helped by the need to look after a pet, others when they joined a voluntary organisation where they were involved with other people. This helped them feel that they were doing something useful. Others used Complementary Therapies such as Reiki or Acupuncture and one person found repeating a daily mantra useful. A change in diet, giving up alcohol and cannabis, GP support, undertaking a regular exercise programme, attending an Art or Music class and listening to relaxation tapes were strategies that helped many to feel that they were regaining some control over their lives. International websites and chatrooms were used by those who had problems sleeping as they could contact other people in different time zones. Both the Internet and local libraries were useful sources for information. Some Service Users attended Anxiety Management Groups and Depression Workshops,

One Service User eventually came to the realisation that it was better to focus on the positive side of a situation rather than worrying about things that were out of his control;

*'I've helped myself just by changing my attitude to life -  
-- not worrying about things I have no control over. If  
they're out of your control, then you have to accept it  
rather than beating yourself up about it.'*



## Denial and Fear

Denial and fear are two strong emotions that can stop us getting the help that we need. It was not surprising that both these emotions were found in the interviews conducted.

### Denial

One Service User realised that she was reacting negatively to some of the things that the CRHT Team were saying to her and that until then, she had been in a state of denial. Another person had a friend suffering from Parkinson's Disease who was receiving inadequate care; she felt bad that her own entitlement to medical care was not as strong as that of her friend.

### Fear

Some people described the fear they felt when experiencing mental illness and encountering mental health services for the first time. Others recalled previous distressing or inadequate treatment which left them even more afraid on this occasion. One Service User recalled a previous negative experience of being sectioned under the Mental Health Act. This exacerbated her current feelings of being unwell. She feared being admitted to hospital and being treated by her previous psychiatrist. Another person was too afraid to leave his home because he was suspicious that medical staff were against him.

There was a fear of the stigma surrounding mental illness and difficulty in accepting that it should be viewed in the same way as a serious physical illness. There were concerns about confidentiality as well as difficulties in asking for and accepting help. A lack of understanding of the feelings being experienced left one person '*shaking and terrified*'. There was a fear of telling work colleagues how bad their feelings were in case they lost their job. When applying for a new job, one Service User suffered agonies of self-doubt at the prospect of facing a selection board. He was worried as to how much he should rely on medication through the process and about the impact on his mental state if it were to be reduced.

There was also a general fear of seeing a psychiatrist for the first time and of being in the unfamiliar environment of a psychiatric unit. Also, some people expressed a fear of reverting back into depression when their treatment came to an end.

## **Awareness of others**

The impact of Service Users' awareness of and perceptions of other people varied from positive to negative. One person felt that she had to be outwardly strong in front of her family in order to protect them from their worries although she found this difficult because of her own illness.

Another person who lived in a small town felt there was a stigma attached to mental illness. This person was aware that some friends who suffered mental illness were not able to find a way of helping themselves, which in turn increased her own distress. Living next to noisy neighbours was stressful. Accidentally meeting a previous partner could be particularly disturbing

On the positive side, one Service User found that she felt useful when she was able to be involved with her family in supporting a family member with their problems. Another, who was nervous about returning to work, was gratified to find that colleagues treated him in the same way as they had done prior to his illness. One person was aware of the support from his family, including the fact that his wife showed no alarm or shock when he self-harmed; he felt that this attitude towards him helped considerably.

## Attitude and Perception of Problems

The Service User's attitude to and perception of their difficulties often changed during the course of their illness. With appropriate support, an individual could progress from perceiving himself as hopeless and helpless to a place where he could begin to understand the causes of the illness and develop his own coping strategies. This meant that, in time, many Service Users managed to become more positive and assertive.

One person found the strength to fight her illness, by striving to develop a positive attitude and focusing on putting herself first by acknowledging that *'life is worth living'*

Another realised that she had spent so much time looking after other people that she had not really existed in her own right: *'I had always been somebody's mother, somebody's daughter, somebody's friend.'* Following her illness, her perception altered to one of three types of people: *'mentors, safe people and people that drain you'*. As a result, she learned to reach out to family and friends, to accept help and support, and to ignore the criticisms from those who had previously accused her of selfishness by *'retiring' into illness instead of looking after her family'*.

Sometimes there was a false assumption on the part of the person in crisis that family and friends would have no understanding of feelings of depression. Where this was not the case and was brought into the open, one Service User was helped considerably in her relationship with family members. The realisation that there were people who genuinely cared about her/him regardless of the illness was often a factor in changing the individual's attitude to the illness.

# Continuity of care from CRHT teams, family and friends

## **Continuity of care CRHT teams**

The importance of continuity of care came up in nearly every interview we carried out. Service Users found it beneficial to have one or two workers with whom they could build a rapport; so that they could get to know each other and work together effectively. It was important not to have to repeat the same information to new workers, especially when the majority of it was distressing. This was very exhausting for some. Whenever a new worker was involved with a person in crisis, a lot was repeated and much time spent doing the ground work afresh. Very little of it was spent doing anything productive either practically or emotionally. Having the same CRHT worker from the initial onset of crisis through to the end helped both the Service User and the worker see how far they had come.

When a CRHT worker had not read case notes prior to a visit caused some to make inappropriate and tactless comments that were very distressing and which could have been avoided.

When an unfamiliar CRHT worker read the case notes prior to a visit, this helped both the Service User and the worker (although it was always felt to be far more beneficial to have a worker whom the individual already knew). People appreciated knowing who was coming to visit them prior to the visit, especially where there were lots of different workers involved.

One Service User who saw more than one psychiatrist found that mistakes were made in relation to his/her medication.

Knowing that they could phone the CRHT at any time was very welcome, even though being aware of this option paradoxically meant they were less likely to use it.

Those Service Users who got to know mainly one or two crisis team workers felt they were able to talk more openly and honestly about what was happening to them.

Regular visits and phone calls were also appreciated. Those who had regular and frequent visits at the initial stages of referral, were helped to adjust gradually to less support thereby becoming increasingly more independent as they improved and as the visits gradually decreased.

Crisis Workers who arrived late for visits increased the anxiety and distress experienced by the service user, especially in the early stages of the crisis.

Quotes from Service Users:

*'I think it's quite an insult to the person who is in absolute crisis to have someone come in and not have a clue who I am.'*

*'I think although people can always look at notes, there's nothing worse than having to go through something that you only went through just the week before'*

*it's exhausting, it's time consuming and it makes you feel they haven't bothered to read it.'*

## **Continuity of care from family and friends**

Continuity of care in general has been a big theme, whether this took the form of continuity of care from services or from family, friends and carers. Service Users found it extremely beneficial to have regular visits from the same individuals together with regular phone calls, and just knowing there was somebody there if needed. Continuity and consistency of emotional and practical support from family and friends, together with having people who stood by them, who were concerned for their wellbeing, came up time and time again. Constant encouragement and patience were appreciated.

One Service User's father wanted to be present at meetings with CRHT in order to help him understand the causes of his son's depression. Another family responded by cooking meals regularly, ensured that medication was taken and took the individual out on trips. Another Service User was helped by a friend who brought his wife to visit him daily in hospital, both of them offering a constant source of support.

# Influence of family and friends in recovery

Family, friends and carers who spent time listening to the Service User, as well as becoming involved in their care planning and treatment, increased their general understanding of mental health distress and, in particular, the difficulties experienced by their family member. They were able to offer more valued support as a result. An example included a family member who accompanied the Service User during sessions with the CRHT worker and who, if the Service User broke down in distress, could then talk to the worker allowing the Service User time to recover their composure.

There was also the case of family and friends who supported and encouraged the person in crisis to maintain control over their life choices. Often, just spending time listening to the person helped reduce the pressure that was experienced. A Church group provided support by ensuring a rota of regular visitors who were prepared to sit and listen for however long the Service User needed. In the case of someone in crisis who couldn't face people the fact that visitors from the Church left flowers and cards with messages of '*encouragement and affirmation*' at her door helped her overcome feelings of worthlessness. Reassurance that came from family and friends who were always prepared to listen, letting the ill person know how much they were loved and valued was a tremendous help in recovery.

One Service User told how; '*the family reassured me that I wasn't going mad and that I was quite within my rights to be feeling the way I was feeling.*'

Another Service User's brother made regular, special long journeys in order to take her walking in the countryside, reassuring her that she was still the same person that he and the family had always loved and that they all '*believed*' in her. She found this particularly useful because at times of depression '*you don't love yourself.*'

Another individual's feeling of self-worth was helped by a friend who pointed out that she had reared two excellent children who were a credit to her proving what a worthwhile person she was.

## **Practical support from family, friends and carers**

There were a variety of ways in which family, friends and carers could offer practical support to someone suffering mental distress. Many Service Users mentioned the invaluable help they had received from those who helped with household chores such as cleaning, shopping and washing. Support with childcare was appreciated by a young mother, sometimes for a night and at other times when she met with the CRHT team. One person's daughter organised her household finances which meant that she avoided getting into debt. Another Service User's mother visited each morning as part of a daily routine that gave her something to get up for. The mother would also make sure that her daughter took the correct amount of medication, they would have coffee together and go on an outing each day.

Friends who kept in regular contact by phoning and visiting were very helpful. One friend regularly took a Service User to the Gym.

In one case, a service user was supported by members of her church who regularly brought her meals to ensure that she ate properly. On the occasions when she didn't want to speak to visitors they left the meal on the doorstep. They told her that *'there's no point belonging to a fellowship if they can't help you and rally round you.'*

Another service user was helped by friends who visited regularly and who would contact the CRHT team if they felt it necessary. They would fetch her medication and suggest outings as appropriate.

## Unhelpful support from family, friends and carers

The attitude and behaviour of family, friends and carers directly affected the Service User's well-being, but sometimes contributed to deterioration in their mental health. There were some people in crisis without family or friends, whilst others were abandoned when they became unwell. This, in turn, contributed to feelings of isolation. Sometimes family and friends wanted to help but suffered such stress that the Service User felt worse. A Service User reported that her family had contributed to her depression and in her view was probably the cause of it. Another person's wife accused him of '*making a fuss*' and became impatient with him. She found his illness 'too stressful' and he felt she was '*passing on that stress to me.*' One person could not confide in a particular family member because he could not rely on confidentiality and '*it would be all round my family.*'

A daughter no longer wanted to see her mother and this led to her mother's feelings of abandonment. Where there was a difficult relationship with brothers and sisters, this contributed to increased stress for someone experiencing a crisis. A Service User was visited in hospital by his family together with his young grandchild. In the presence of the Service User the family told the child that if he didn't behave the Service User would be kept in hospital. Another person's friend told her that she should be able to cope with her illness without the help of the CRHT team and that she should listen to her instead. Understandably all these situations proved extremely unhelpful.

### Attitude of Family and Friends

The attitude of family, friends and carers varied dramatically from understanding and empathy to negative attitudes, comments and behaviour. The verbal expressions used impacted on the Service User even in instances where they were intended to be well-meaning.

Unhelpful expressions included:

*'You'll be fine, you won't feel like this tomorrow.'*

*'Come on, cheer up, what have you got to be depressed about, you've got a good life.'*

The husband of one Service User told her to '*pull her socks up.*'

Friendships often quickly deserted an individual when they became unwell. Family's, friends' and carers' lack of understanding and knowledge about mental health difficulties proved not only to be unhelpful but also increased feelings of isolation. In those instances where they initially lacked understanding but then became involved in the Service User's care planning, they were able to offer valuable support. An example of this was the father who was present during the Service User's sessions with the CRHT team. This resulted in an improved understanding of his son's problems. Another Service User had friends who kept in close contact and would phone his parents if things deteriorated.



There were those who wanted little contact with family, friends or carers, although as their condition improved, they often realised that this attitude had been unhelpful and they came to appreciate the efforts made by others to keep in touch regularly.

It was unhelpful when family, friends and carers felt ashamed that someone close to them had a mental health difficulty.

From one Service User:

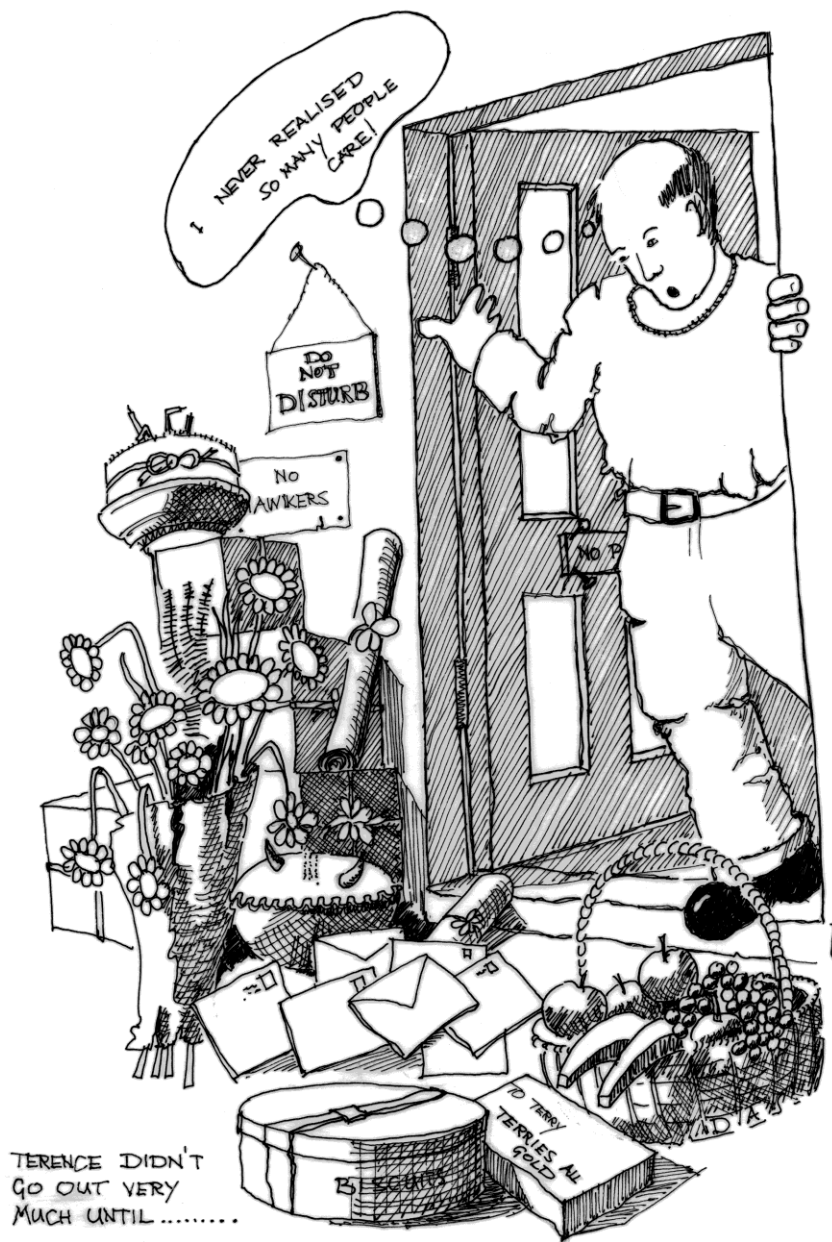
*'It's sort of like brushed under the carpet with them, you know, that's the sister who's a bit, you know, lost the plot.'*

Another family tried to ignore the Service User's illness by treating her in the usual way but would not trust her to have contact with nephews and nieces.

Unconditional love combined with a non-critical and non-judgemental attitude by family, friends and carers were the helpful ingredients in a good supportive relationship with the Service User in a time of crisis. One family refused to treat a Service User differently from the way they had done prior to the illness. They did not judge but accepted the Service User's self-harming. One person was grateful that his wife and family did not get upset when he self-harmed as he knew he would have felt even more frustrated if he caused them distress. When he returned to work people treated him as they had done previously which meant that work also helped his recovery:

*'rather than say the wrong thing, men just don't say anything a lot of the time, so that's been really good.'*

Another Service User was helped by the fact that the family still included him in all family decisions, activities and outings. The unconditional love one person received from her children together with being able to share things openly with her family was immensely helpful. The disclosure of family members who admitted to having their own problems with depression, helped a Service User to reach a better understanding of his own problems.



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GO OUT VERY  
MUCH UNTIL .....

# When CRHT support helped and when it didn't.

Different teams worked in different ways. However, we found that even within teams there was a big difference in the care received by the mental health service users we interviewed. This was due not to the way the team was established but rather to the different ways individual staff worked within the team.

Core themes arose throughout the interviews about what helped and what hindered recovery. These themes are identified in other sections of this report. They related to not only the services available including input from the Crisis Resolution and Home Treatment Teams, but also to the support from family, friends, carers, and the wider community. Continuity was a key issue that arose time and time again throughout every interview.

For services, continuity meant having someone work with the Service User throughout a crisis from onset through to recovery, and where this was not delivered the interviewees felt it hindered their recovery and caused distress.

The attitude of CRHT workers was reflected in the way mental health service users felt they were treated and impacted on how involved the Service Users were in deciding their own treatment and the type of support they received.

The workers who made a positive difference in helping an individual to recover evinced good interpersonal skills and could build up a supportive two way relationship relatively quickly. They were the same workers who at times worked '*outside the box*' in order to meet the individual's needs. This meant they sometimes 'cut red tape' in order to work effectively. For example, on occasions they worked with someone longer than they were meant to. However the effect of working in this way was perceived by the Service Users as very effective and as a result, they were less likely to access longer term support from services; instead being referred back directly to their GP.

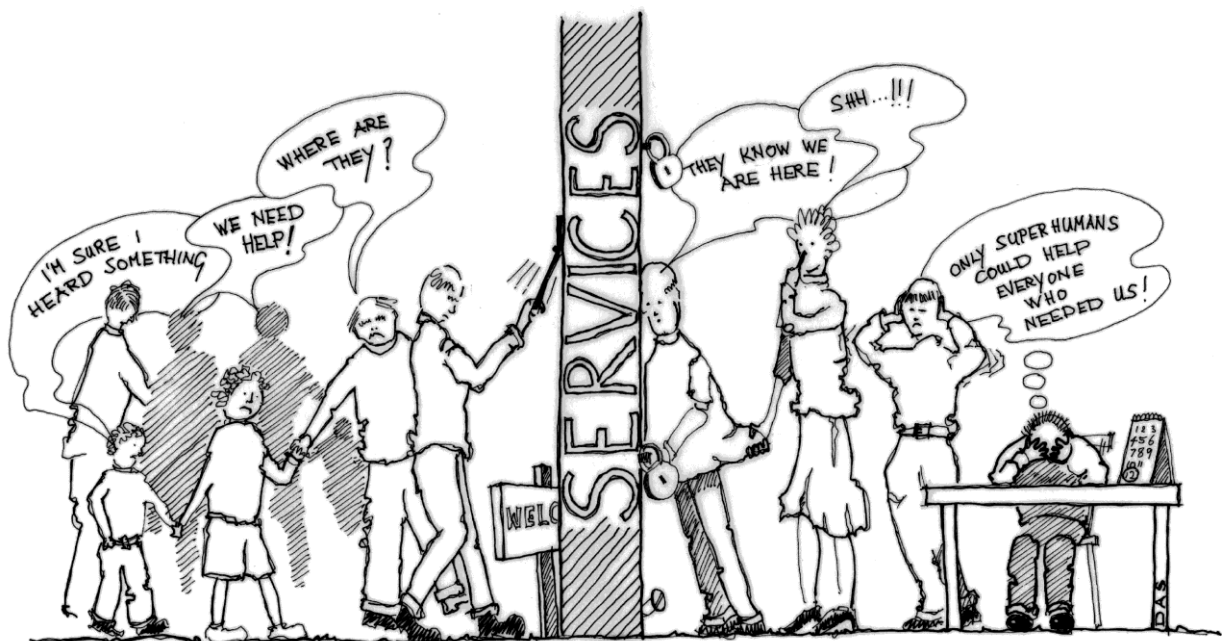
## **Awareness of and referral to CRHT teams**

Awareness of the CRHT services and how people ultimately accessed them, was one area that could be improved (and probably would benefit from further research).

Most people in a crisis knew that they needed help but had no prior knowledge of the existence of CRHTs. Some had already accessed their local Mental Health team or were waiting for an initial appointment. Long waiting times for a new referral or long gaps between existing appointments meant that people who were relapsing or entering a mental health crisis often deteriorated whilst waiting: sometimes this reached the point whereby they became so unwell that they had to be admitted to hospital (some were close to compulsory admission under the provisions of the Mental Health Act).

The majority of people were referred to the CRHT by their GP and consequently it depended on the GPs' knowledge, attitude and experience of mental health issues on whether the process was easy and helpful. Some GPs had little experience of dealing with mental health problems. Most people we interviewed did not find it easy to get the GP to understand the difficulties that they were experiencing and to accept that they needed help quickly.

A & E was regularly used by people, who were having a mental health crisis, as a means of getting help, occasionally taking the form of overdosing or self-harming. It was usually as a result of a nurse or health care worker in A & E being aware of mental distress and/or the existence and referral patterns to CRHT that the person managed to access the team. They did this either by a direct referral from A+E, phoning the CRHT directly themselves (once they were given the number) or by revisiting their GP and requesting a referral. A&E doctors who assessed patients presenting in A&E with mental health crises were perceived as having little patience or understanding of the distress involved.



## **First Meeting with CRHT Teams**

The impression of the initial meeting with a CRHT Team impacted on the Service User's overall future experience of the service. Everyone was anxious about the first visit but usually found that the Team workers were reassuring and put them at their ease. Most people preferred the meeting to be in their own home rather than in a clinical setting or a hospital, and preferred to have no more than two workers present. They felt that talking about their feelings with a larger group was their personal choice. Initially it was important to be given unrestricted time to talk in order to explain fully the background to their crisis and the difficulties they were experiencing. Discovering, during the course of the first meeting, that someone would be there for them or contactable at a time of need was extremely helpful. CRHT workers who appeared unperturbed by manic or bizarre behaviour allowed Service Users to regain their composure more easily.

### **Building relationships - CRHT Teams**

Building a good relationship between the Service User and the CRHT Team as well as with individual workers proved to be vital. When they felt familiar and at ease with each other, the Service User felt supported and could begin to move on. Support that was non-directive, in tune with the situation of the Service User and delivered at their pace was the most valued. This type of relationship was more likely to develop when there was just one CRHT worker involved with the Service User.

Difficulties in building a relationship arose for a number of reasons mainly:

- there were a variety of different CRHT workers involved
- workers had not read Service User's case notes and seemed to know little about the person
- CRHT workers did not consult with or involve family and friends

Developing an honest, good quality, two way relationship was the key to providing effective and helpful support. It was essential to focus on the positive aspects of the Service User's life, whilst at the same time building a therapeutic relationship that was friendly and trusting. One Service User received a letter from the CRHT worker in which the positive aspects of her as a person were emphasized. This helped her to move on in her recovery after discharge.

*'they aren't directive, they very much work with how the person is feeling, and it was once I'd got that acceptance from them, of me coping, I started to gel with them, we started to look at more constructive support.'*

## Attitude of CRHT Teams

*Listened to, respected, valued, understood*

Towards the end of the interview, we asked people if they felt listened to, respected, valued and understood by the CRHT Team. Generally, the reply was short unless there were areas of concern which they wished to explore. We considered that short replies at that stage of the interview were a likely consequence of tiredness and therefore compared their replies to these specific questions with the transcript as a whole. We found there were inconsistencies in their responses with the earlier ones being more descriptive and informative. For completeness, we have included some of those earlier comments made by Service Users regarding the attitude of the CRHT workers (but generally not the psychiatrists working with the teams). Even within the teams, there was a variety of responses from Service Users regarding the various attitudes of different CRHT workers.

Responses varied:

*The Team 'were the only people who I did actually feel listened, properly listened to what I was saying, and understood my frustration, and how I felt, because the doctor didn't, the therapist at the hospital didn't. Anybody can listen but very few people hear what you're saying, and they hear.'*

*The Team was 'gentle but firm; they know what you mean, they understand and they're supportive in a productive way rather than just tea and sympathy. They very much work with how the person is feeling, they really wanted to work with me and not to me, not directive, we started to build a therapeutic relationship.'*

*The Team 'shrugged me off like everybody-else had done.'*

*The Team 'treated me like a child.'*

Many CRHT workers were able to make the Service User feel at ease, were able to share a laugh with them, were caring, thoughtful, understanding and non-directive.

However, some Service Users felt they were not understood and not listened to. At times CRHT workers were judgmental, cold and uncaring. Some Service Users strongly expressed their concerns about the attitude of individual workers even in teams about whom they had made generally positive comments. This was invariably more apparent where individual CRHT workers had not read the individual's case notes prior to the contact.

The level of crisis as perceived by the CRHT workers affected both the time given and also the attitude of the worker towards the person in crisis. Often Service Users were only given 5 minutes to talk on the phone when they felt that they needed longer. The result was that the Service User felt unimportant and not cared about. This had a negative impact on the overall relationship.

### **Access and Response in a Crisis**

The majority of Service Users knew they could phone at any time of the day to access support, in addition to having other helpline numbers that they could ring if necessary. Most CRHT teams emphasized the fact that they could be phoned at night which was greatly appreciated. Paradoxically, the very fact of knowing that support was always available meant that people were less likely to phone unless they felt they were in acute crisis. Knowing that someone was there if and when needed helped people feel safe.

When Service Users actually needed to contact the CRHT in a crisis, they found a mixed response. Some CRHTs were easier to contact than others. The response varied from an answer machine message, a few minutes of allotted time or in some cases as much phone support as was required, followed by a home visit. Some CRHTs were very hard to get hold of, especially if they were also covering an A & E department.

When a Service User needed a home visit, again there was a mixed response. Some people received a visit within the hour, others within half a day, whilst some had to wait for several days. The CRHT perceptions of the level of risk to the person in crisis and of the individual's diagnosis meant that they were not always rapid in response.

Some CRHTs took the view that if a crisis lasted beyond a few weeks, the Service User should be referred to the Community Mental Health Team. Some Service Users in this situation felt that they no longer received the support they needed, and thought they were being passed on in order to be rid of them. These Service Users took the view that the CRHT did not understand their crisis or the support they required, and that they lacked recognition that a crisis can last longer than a predetermined number of weeks. All the people we interviewed, who felt they had been placed in this situation, were referred back to CRHT on numerous occasions. Subsequently they passed back and forth between the teams, sometimes receiving the support they needed and at other times not. This proved to be unhelpful in their recovery and detrimental to the therapeutic relationship between the Service User and the staff working with them.

Some CRHTs allowed the individual who had been discharged to phone them directly should they require help in a future crisis. Where a Service User had been discharged knowing that they could ring the CRHT number at any time in the future, they found this to be very positive approach. It helped to lessen their anxiety which in turn reduced the likelihood of a future relapse.

## **Discharge Support**

Service Users' experiences following discharge from CRHT support were quite varied.

One CRHT Team maintained contact with a Service User during the crucial period of his return to work. Some CRHT Teams gave reassurance that they could be contacted by phone at any time in the future should the person need the support of someone to talk to; whereas another team discharged a person after a set number of support sessions regardless of whether the Service User felt ready. He then requested a referral to either a Psychologist or a Psychiatrist but as this did not happen, he felt that in the event of a relapse he would be forced to find support elsewhere.

There was often a time gap between finishing CRHT involvement and starting a course of psychotherapy. Some Service Users found and booked their own places on a variety of self-help courses such as Stress and Anxiety Management, Coping with Depression, Confidence Building Workshops and Relapse Prevention Strategies.

Some Service Users were discharged from the Acute Wards to a Recovery Team whilst others were referred back to their GP. One person was given a Care Plan, saw a Psychiatrist at regular intervals, a CPN weekly and also was assigned a place on a WRAP course (Working towards Recovery Approach Programme).

An unfortunate Service User who was transferred from a CRHT to a Day Unit was not able to attend owing to practical difficulties. He had not received help with these difficulties by the time of the interview with the researchers.



## **Advance Directives**

Out of 21 interviewees who were asked if they had been offered information on Advance Directives, only one answered in the affirmative. No-one else was aware of either the existence or meaning of an Advance Directive. It is of interest that the one person who was offered information, was treated by the same Team as three others who were not offered any information about Advanced Directives. This implies that it was not a clear part of that Team's policy but rather a consequence of the individual worker's view of what was appropriate. Two interviewees said that they would have liked to have had the opportunity of being given information on Advance Directives had it been offered to them.

## **Planning for the Future**

Service Users were usually referred back to their GP for future monitoring.

Some CRHT Teams helped Service Users focus on goals for the future and offered future phone contact in order to provide reassurance and to help avert a relapse if needed. As indicated above, this was particularly useful for the Service User returning to work, who was promised continuous support during that time.

Following the completion of treatment from a Psychologist, one Service User was given a written summary of the work they had done together, as well as a list of relevant helpful books and services that might be used in the future. Another Service User will continue regular visits to both a Psychologist and a Psychiatrist until she is completely well.

However a person scheduled to attend a Community Mental Health Clinic has had three appointments cancelled and at the time of the interview was still waiting for a fourth, whilst another was waiting for the therapy which had been promised at discharge. In one case, however, the CRHT Team were obliged to discharge a Service User after a set number of visits which he found quite frightening as he was not offered any future support.

*'It was just that short term care was limited and there was no kind of long term solution that was immediately available. There was no bridge in between the short term and the long term.'*

# **Support from Other Sources**

## **Samaritans and other help lines**

Service Users received beneficial support from a variety of sources. Some found talking to The Samaritans helpful whilst others valued talking to NHS help lines.

## **Voluntary work**

Being involved in Voluntary Work, where usually there were cheerful and compassionate people to talk to, helped to distract some Service Users from their problems.

## **Respite from caring (for their son or other family member)**

One Service User with a disabled son received support from a Care Worker who looked after her son while she had some time to see friends. The Sure-Start scheme was able to help a mother by looking after her child whilst a worker took her to see a doctor and arranged for a Health Visitor and a Counsellor to support her.

## **Church**

Belonging to a Church was usually a good source of support as arrangements could be made to ensure regular visits from Church members.

## **Internet**

Finding information on the Internet as well as Chat-room sites were used by some people to good effect.

## **Therapies**

Cognitive Behaviour Therapy, alternative therapies such as Acupuncture, seeing someone from Patient Advocacy, attending Anger Management courses and participation in the activities on the Hospital Day Ward were all cited as helpful.

## **Helpful support from pets**

Having a pet could be helpful. One Service User valued the unconditional attention she received from her dog which gave her a reason to get up each morning to walk it. When the dog died she bought another as this motivated her *'to keep going.'* It was something to focus on and helped distract her from how she was feeling. Another Service User found comfort in his three cats.

# CRHT in Recovery – what helped and what hindered

A variety of things have helped and hindered recovery. Identifying these proved quite complex because every person is an individual with a different set of circumstances, upbringing, personal expectations, social networks and life experiences. By recognising and understanding the Service User's life experience, CRHT workers, as well as family and friends, can help an individual recover more quickly and reduce the likelihood of relapse. When CRHT workers were able to build a relationship with the Service User and their family by listening, recognising their needs and working at an appropriate pace, they helped recovery. Sometimes this meant that CRHT staff had to work creatively by 'cutting red tape' and spending more time with people than was expected or allowed for by their managers.

It is impossible to identify every factor that affects recovery because each person is unique but we have identified key themes in order to inform clinical practice and support areas of future development within CRHT services.

## **What helps Recovery?**

Recovery was helped when:

- Service Users gave themselves time and rest
- there was effective service provision that met individual needs
- the causes of distress were identified
- there was practical and emotional support from family and friends
- Service Users were helped to take control over their own lives and their support needs
- they were helped to make changes in the way that they viewed themselves and their lives
- they were helped to identify a purpose and meaning in their life.

## Services

CRHT were able to offer a variety of effective support. One Service User reached the stage where she felt

*'the decision should be to move on, because I think it can get to the stage where I think it's unhelpful to keep going over and over and over, and it makes you concentrate more on things and I think this is unfortunately what has happened to us, and this is my life and I have got to get on with it really.'*

In this instance, she felt supported and encouraged by the CRHT in her decision that it was time to move forward.

Medication helped another in his recovery.

*'I think the importance of medication at a time of crisis is that it takes you to a place where you're in a position to recover, and although you receive a lot more tablets than you would otherwise receive and want to receive, it enables you to go through the recovery process.'*

In another case, previous treatment from a psychologist had been helpful and CRHT were able to refer him to another psychologist to resume therapy.

CRHT helped another Service User to work on and improve her relationship with her daughter and helped her maintain her social network.

Several people cited the effective help and support from the crisis team including the psychiatrist working with them.

## **Identifying the cause of the problem and increasing understanding**

CRHT were successful in helping recovery when they were able to help the Service User understand the cause of their problem. The Team could then provide helpful and appropriate written information together with practical support.

## **Activity and purpose**

CRHT helped recovery when they encouraged Service Users to identify goals and to draw up an action plan to re-establish an active, meaningful week, e.g. undertaking a regular gym programme, or becoming involved in voluntary work; thus increasing companionship, understanding and friendships. Encouraging people to record their daily experiences and feelings in a diary meant that they could reflect on their progress.

## **Other things that helped recovery**

CRHT were able to help the Service User's family by offering appropriate information and practical support to them.

Another person received a period of intensive support from an Occupational Therapist

*'I got put onto the OT guy. He kept me on between that gap between being discharged. I probably did about three months of work with him. So I was probably one of the very lucky ones. He was more specific with his help. He identified the self-image problems, the trying to turn round the negative thinking. He was more intense really.'*

Giving up heavy drinking was found to be of considerable help. Others used the internet (e.g. Facebook and chat lines for people with depression around the world); which was particularly useful at night when it was difficult to sleep. Rediscovering a previous interest or hobby such as a talent for art was also found to be helpful.

## **What hinders recovery?**

Recovery was hindered in a variety of ways. Negative attitudes and behaviour from staff and services, and also from friends, family or the local community impacted on recovery. Often, there was stigma, especially when a diagnosis was provided. Sometimes medication was prescribed without the necessary ongoing follow up. There were times when individuals had developed their own coping mechanisms of self-harm, including drinking and drugs which made the problems worse. These behaviours were perceived as harmful options by those who felt they did not possess nor were offered alternative coping strategies. Many Service Users wanted to understand their feelings and the meaning of their distress but felt that they did not receive the unconditional support both in time and resources quickly enough. Sometimes, there was a lack of information about mental health and the variety of support that can be made available by statutory services, as well as other sources. A lack of continuity from staff, friends, family, GPs, or other sources of support, for example from their church was seen as unhelpful. Having regular contact and visits from someone was very important (rather than irregular or haphazard ones).

## **Services**

Recovery was hindered in instances where there were long waiting times for referrals to other services (e.g. community mental health teams, psychology and other therapies) during which some people were left to their own devices. There were other examples of no follow-up after discharge.

Recovery was hindered when:

- the Service Users had to wait for further therapy or were given unrealistic waiting times resulting in deterioration in their mental health
- owing to a perceived lack of funding Service Users were told they were lucky to receive any input
- someone needing long term psychotherapy in order to avoid future relapse was offered only limited short term help from the CRHT
- persistent questioning by CRHT staff about negative past experiences increased depression and feelings of hurt for some people
- the Service User turning to alcohol after feeling that he was unsuccessful in getting help from both the GP and CRHT on a number of occasions
- a lack of funding for support groups and helpful networks
- a Service User felt that the psychiatrist thought she was wasting their time which resulted in her not phoning when support was needed

- changing doctors during a sensitive period in treatment was followed in one case by a rapid deterioration
- CRHT staff were perceived by a Service User as cold, unsympathetic and lacking genuineness
- a lack of short term crisis support meant that a Service User felt they were discharged too early from CRHT
- a lack of CRHT availability when phoned by a Service User needing one-to-one support in person rather than on the phone
- CRHT spent too much time filling in questionnaires and discussing the beneficial things a Service User might like to do, without actually supporting them in doing these things
- a Service User who did not want to attend a Mental Health Day Centre but was persuaded to do so by the Mental Health Team felt this had hindered his recovery
- unhelpful, critical attitudes and comments from pharmacy staff towards Service Users
- a very negative experience of admission to an Acute Ward
- an Occupational Therapist gave inappropriate recommendations to one Service User showing a lack of understanding
- an A&E doctor was very unsympathetic and expressed his resentment at being woken up at night even though he was on duty
- a previous negative experience of using Mental Health services led a Service User to a fear of using them again in case of being placed on a Section of the Mental Health Act.
- a hospital did not refer a Service User for any support in dealing with a traumatic accident. She wanted counselling and asked her GP. The waiting time was 6-9 months and she hit crisis point before then
- a lack of support post-crisis leading to a possible relapse



CLAUDIA WASN'T SURE IF ANTIDEPRESSANTS  
WOULD HELP VERY MUCH!



# A brief summary:

## Recurrent Themes

### **What we found helped recovery**

(whether from staff, friends and family or other sources of support):

#### ***Reassurance***

Just knowing someone was there who had some understanding of what was happening, either in person or contactable at the end of the phone.

#### ***Positive relationships that showed***

consistency, acceptance, understanding, listening and hearing, together with being non-judgmental

#### ***The Service User enabled and involved in recovery***

having control over their own life and making their own decisions and choices of treatment.

### ***Other factors:***

#### ***General Practitioners***

Having a supportive, non-judgmental GP proved to be helpful

#### ***Practical support***

Having practical help with household tasks, shopping, cleaning, gardening and help with child care

#### ***Access and flexibility***

Having access to support, whether it was from services, family or friends that was flexible.

**What hindered recovery was:**

***Negative attitudes and behaviour***

From anyone involved including CRHT staff or services, friends, family or the community

***Service User Expectations prior to crisis team involvement***

The individual Service Users' expectations of the service that they should receive. Both low and high expectations affected their perception of the quality of the service and the support delivered

***Lack of continuity***

Where there was lack of continuity from staff, friends, family, GPs or other sources of support e.g. church. Having regular contact and visits with someone was important.

***Lack of appropriate/organised follow-up***

Long waiting times for referrals to other treatments e.g. psychology and other therapies. A lack of follow-up after discharge from CRHT, even while still accessing other services. Long time gaps between discharge from the Crisis Resolution and Home Treatment Teams and access to other services for longer term support.

**Summary:**

**In essence, having someone who develops a good relationship with you; accepts you; listens; is non-judgmental; is consistent; involves you all the way; provides reassurance and helps practically; these are the main things that help someone during a crisis. It didn't matter if family and friends did not have much awareness of mental health as long as they were prepared to listen to what the person him/herself was going through, learning and adapting along the way.**

# **Emotional demands on Crisis Team Staff and Family**

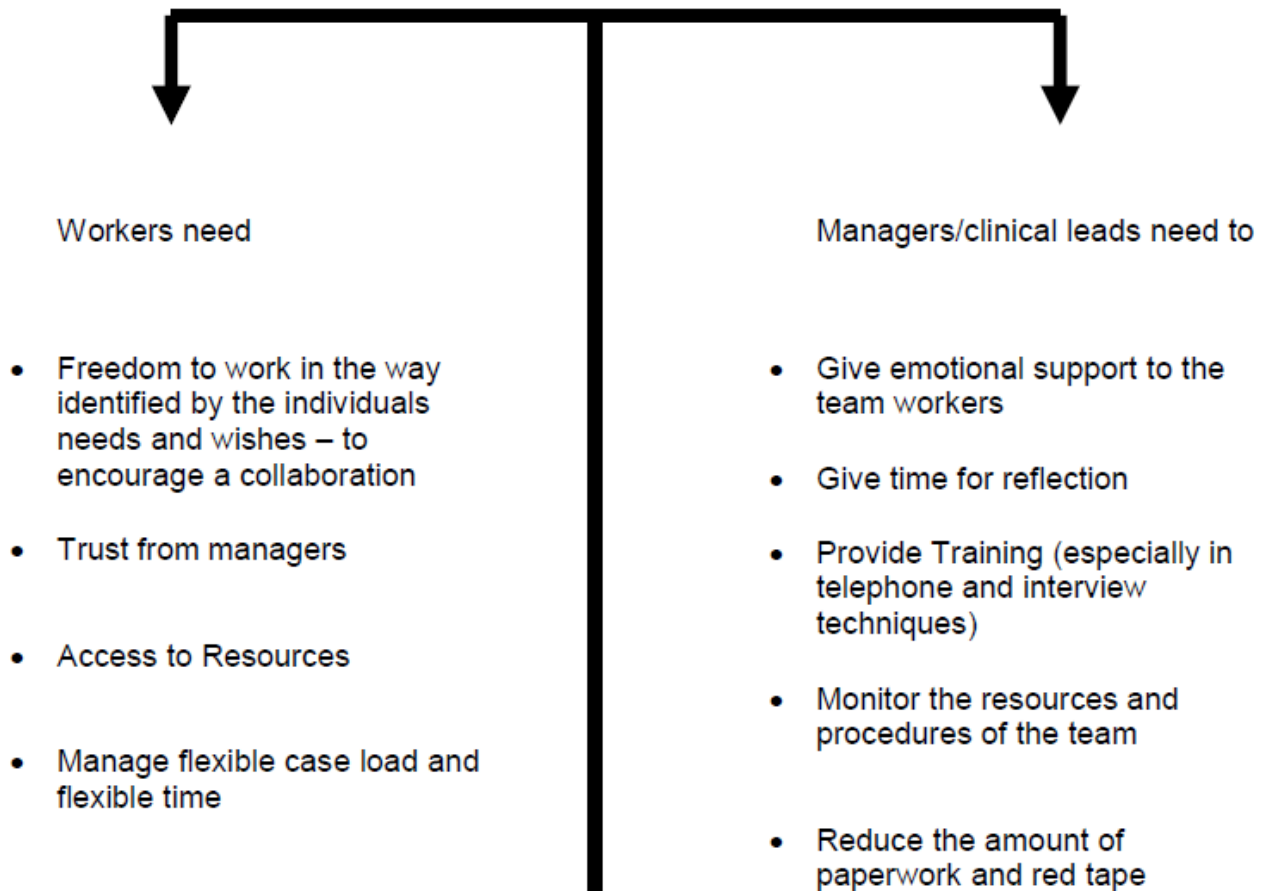
When working with anyone who is going through a crisis, the person giving the support, whether that is a friend, family or mental health worker, will find it emotionally demanding. Supporting those who help others in a mental health crisis, providing them with information, enabling them to have the tools to do the job and giving them time out are all essential. Friends and family often needed information and reassurance and where CRHT workers were able to do this, the support that friends and family could give was more positive with better outcomes. Workers who were worn out, time limited, overloaded, burdened with red tape and restrictions but who also cared and wanted to help people through a crisis clearly found it emotionally draining.

## **The essential Quality of the therapeutic relationship**

Every person has their own individual needs and therefore there will never be any specific intervention that will work for all. It is not the type of therapy or the specifics of the intervention that helps. Many research studies have shown that it does not matter what type of therapy or technique is used but rather it is the quality of the therapeutic relationship itself that succeeds. This research has confirmed that finding by scanning the work of Crisis and Home Treatments teams where several workers are involved. It was not necessarily the type of support that was provided or the way a team theoretically worked that provided a good or negative experience for the Service User. It was the quality of the relationship with each of the team workers and with family and friends that proved to be the key factor in recovery. The qualities needed to provide these positive therapeutic relationships were the ability to provide reassurance in a safe and non-judgmental manner. Limitations placed on some workers which did not allow them to provide support in this way (i.e. tailored to the individual), meant the workers were perceived as often drained and worn out leaving the Service User feeling their needs were not being met.

# What can we learn from all this?

These were our first thoughts from doing this research on how managers and clinical leads can support workers, and what workers needed to have and to do in order to effectively support people through a mental health crisis.



Workers can then provide effective support by

- 😊 meeting the individual needs of the people they are working with
- 😊 enabling a fuller recovery
- 😊 reducing the likelihood of a relapse
- 😊 people needing minimal support in the future

# What Next?

## **Learning from the findings**

We need to work together to discuss the findings from this and similar research studies so that we all can learn how to use the resources of the crisis teams effectively. There is no point in doing research for research's sake. We wanted to do this project so that positive changes could be introduced and areas of good practice duplicated across other teams.

## **Dissemination**

We will continue to disseminate the findings of this research in order to help in this process.

## **Potential Impact?**

This depends on you as individual workers, as teams and as managers or clinical leads of the services. However, we would encourage you to continue to work with the people you are supporting through your service but also to start thinking about how you could move forward. There were some elements of really good practice within some of the teams which could be shared. The areas of concern we found should not be seen as a bad thing; unless identified they cannot be rectified. We believe this research can stimulate change and be used as a positive tool to make a real difference to the quality of care people receive. The Crisis Resolution and Home Treatment Teams are a much needed service and when they work well, they make a huge difference between someone entering long term secondary services that may be needed for many years or even a lifetime and someone making a fuller recovery, returning appropriately to the care of their GP.

Other types of services could also benefit from this research. Firstly, the results are relevant to any service which provides support for anybody going through a difficult patch. Secondly, the way we have conducted the project can provide a good model for conducting future research.

## **Suggestions for the Future**

In order to remain compliant with Policy Implication Guidance (PIG), many trusts had to create teams by moving existing staff from various other duties. Assumptions were made. For example, planners believed that staff working on wards or in community teams could transfer all their existing skills without difficulty to the new crisis teams. This research project has identified particular components of the therapeutic relationship which do not always work well. The first is the ability of staff to provide assessment and support over the telephone. Many staff assume that they are doing this well but it is clear that Service Users have a different perception. Most industries who work over the telephone or internet have very specific training to ensure that their staff have the necessary skills to work in this way. They also put in place monitoring programmes, with which all of us are familiar; the usual advice that the call is being recorded for training purposes. The NHS does not appear to undertake this approach but perhaps that is worth considering in the future. Similarly, we suspect that many staff will be surprised to hear that the Service Users they speak to do not always feel that they are being listened to. Some feel that they are being dismissed and not heard. In a commercial setting, training programmes would be put into place to deal with this issue and interactions monitored to ensure that the quality of the relationship is as good as it can be. This study shows that the quality of the therapeutic relationship between the Service User and Crisis Team members is a core concern.

Putting these two points together, it is clear that there is a need to train staff for specific skills in telephone and personal one-to-one interviewing (especially in a team based organisation where several people may undertake the same role over a number of days). Once training is complete a second issue arises. The interactions need to be monitored by a third party and preferably by other Service Users who are themselves trained for the purpose. Having identified what hinders and helps recovery, we feel that these are two important lessons from the research which should not be lost and hope they will be incorporated in the ongoing work of crisis teams.

## **Further areas of research**

This project has identified further areas of useful research. Two key areas include research into supporting Carers and the Carers' experience of the CRHT teams. We need to know more about the general awareness of and access to the CRHT teams, as this can influence their effectiveness (especially among GPs and Accident & Emergency Departments).

## **Diversity of participants for this study**

Although we invited everyone who had accessed the Crisis Resolution and Home Treatment Teams in the 2 week census period to be a participant in this study, we recognise we interviewed no one from ethnic and other diverse communities or indeed any one whose first language was not English. This is obviously an important group of people with potentially different needs. Two issues arise; the first is that research is needed to look at the needs of both BME and other minority groups/disabilities (impaired hearing or sight, learning difficulties etc), and secondly it raises questions about who may or may not be accessing the CRHT teams in the first place and whether some groups are being excluded.

# Moving away from us and them

There are many different and separate groups involved in the work of Crisis Teams including commissioners, frontline staff, managers and clinical leads, service users and carers. All these groups have different perspectives, priorities and interests. So when we talk about 'us and them' we are not just talking about two groups but many. Indeed some individuals fall in more than one group which results in more confusion. However, we all want the same ultimate goal which is a good quality service meeting the needs of those who access Crisis Teams and work in them. The question is how can we work together to achieve this goal. Questions yet to be answered:

- ***How do we move forward together?***
- ***How are the actions decided and then taken forward as a result of this research?***
- ***How are the changes made, monitored and further developed?***
- ***What is the best way to involve all stakeholders in this process in a practical way?***



## Working Together

Different groups working together will inevitably lead to some conflict. During this research we have also experienced conflict of ideas between people with different perspectives. This was not a negative conflict because we have talked, listened and worked through these difficult areas respecting each other's views. In this way we have grown to understand each other's perspectives and identified ways we could move forward in the research process. A similar process has to be repeated in the delivery of CRHT services. Different perspectives and conflict should not be seen as a barrier nor stop us from working together. In the end, it can lead to very positive outcomes with real, meaningful collaboration and group working.

The process we have undertaken as a team is a useful model for all service providers and mixed teams whether this is the CRHT teams, community teams or acute admissions. A barrier to true co working could have been the power imbalance. One of the things that has helped us address the power imbalance within our research team has been having a service user as the chief investigator. In general staff hold more perceived power because of the nature of their working role. When involving people who have used services, although when work is on an equal basis, this power imbalance does still have an effect, especially on the confidence of the service user to speak as openly. This could be equally true for any team made up of people from different positions of power e.g. managers, staff, clinicians, service users. It can be quite a challenge adopting this approach at first as there is a lot of adjustment on all parts to be made but it has been worth it. Simple things like the changes in the way we all used communication and jargon, the way meetings were held and where and any areas of concern were more easily expressed.

This research would not have been the same if it had been entirely made up of service user researchers, nor would it have been beneficial if it had been entirely made up of clinicians and academics. The study required a wide variety of perspectives to be successful. It has been as a result of these challenges that we have been able to work together: the result is that we have learnt so much, not just about each other and the detail of the project itself but also about ourselves. When forced to see a psychiatrist as Service User or Carer in the past, few of us contemplated the thought that one day we would work alongside a psychiatrist as co-researchers (let alone two or more!). But the relationship cuts two ways and we feel we have benefited as a group and as individuals. We have all discovered things about ourselves that we would never have otherwise realised!

# Jargon Buster

## **Advance Directive**

Instructions given by the Service User specifying the things they do not want to happen in the event that they no longer have the capacity to make their own decisions owing to a crisis (this is always done at a time when the person is well). E.g. someone might express a wish to refuse in advance any ECT – Electroconvulsive Therapy - or some types of medications. They can be done verbally but it is best to have them written and witnessed. Seek advice if completing one.

## **Advance Statement**

Instructions given by the Service User specifying the actions s/he would wish to be taken for their health and wellbeing in the event that they may no longer be deemed to have the capacity to make their own decisions owing to a mental health crisis. E.g. 'I would like my cat to be looked after by a neighbour and not put in a cattery if possible.'

## **AMaze**

A research group made up of people who have accessed mental health services or who have experienced a mental health crisis or who are Carers. All the members have been trained in research techniques, qualitative analysis and interview skills and have undertaken this research in collaboration with academics, clinicians and other staff members.

## **Carer**

A family member or friend who looks after the Service User.

## **Care Plan**

This outlines the nursing care to be provided to a patient and is the result of an assessment of the patient's needs. It focuses on minimising and then solving the identified problems.

<b>Collaborative Approach</b>	In this case the research was undertaken in an active partnership between Researchers, Service Users and Carers. The project was Service User led whilst in collaboration with others.
<b>CRHT:</b>	This is the Crisis Resolution Home Treatment Team for people experiencing a mental health crisis.
<b>Dissemination</b>	Sharing the research information and findings with other interested parties.
<b>Insider Researcher</b>	Someone with direct experience and personal knowledge of the subject they are researching, in this case Mental Health Services.
<b>Research</b>	In terms of this project: identifying important questions and finding answers about what the individual experiences of mental health crisis are like, the support received and what was beneficial.
<b>Service-User</b>	Someone who is using or has used Mental Health Services. In the context of this research project Someone who has used the service provided by the Crisis Resolution Home Treatment Team [CRHT]
<b>Service User led</b>	This is where the research or project is entirely led by people who have used the mental health services.

# Reflections of the Research Team members

## Val Stapleton (2009) Mental Health Carer Researcher

### Why I became involved in this particular research project

At a personal level, this project appealed to me because of my own very negative experience of attempting to access CRHT services three years ago in my role as a Carer. I was interested to see how the various teams presently work and if they meet the needs of the Service Users. It seemed to me that Service Users and Carers who have firsthand experience of what it is like to suffer a Mental Health crisis and, who undergo training in interview techniques, are well placed to facilitate an encouraging atmosphere in which the Interviewee will feel at ease, will be able to describe their experience and say what helped or hindered their recovery. I felt that this work had the potential to really make a difference in one aspect of mental health care.

### How the group collaboration and dynamics developed

As a Carer working with Service Users, the process of undertaking this research has for me been a learning process, and with the experience of working on this research project collaboratively with Service User researchers I have been able to gain an insight into the different experiences of Mental Illness. There have been four stages in the Research process that we have undergone together:

- Coming together as a group of very different individuals who were mainly strangers to each other, in order to undertake the training in Interview techniques. This training was led by two Service Users which gave the training process an added dimension.
- Working in a pair to conduct the actual Interviews.
- Meeting together as a whole group to look at the Interview transcripts and to begin work on the findings before continuing in pairs.
- Preparing the report together and to disseminate the findings.

Over time we have bonded together as a strong group in which each one of us has equal status. We recognise that each member brings something slightly different to the group both in terms of individual personality, in personal strengths and skills, and in life experience. It is true to say that we have become good friends.

## **The perspective I was coming from and how these have changed**

As a Carer for my daughter when she experienced Mental Illness some years ago I tried without success to access the Crisis Team which resulted in our not using the service as it was then. I was interested in being involved in this research project in order to discover if and in what way Crisis Team Practice had moved on since then.

However, a bonus for me as a Carer involved in this research project has been the fact that I have gained a better insight into my own daughter's experience of her illness as well as into the experience of the people we interviewed. This insight took me quite by surprise during our Training in Interview Technique when we had to undertake Role-Play in groups of three, one person taking the role of Interviewer , another taking the role of Interviewee and the third person being the observer who gave feedback on the actual interview. The experience of role playing my daughter actually started to open a window of understanding on how it had been for her and I could empathise with her. During one of the Research Interviews the Interviewee said of their experience of their illness that:

*'anybody can listen but very few people hear what you're saying.'*

The Interviewee was referring to how good their CRHT Team worker was at listening and understanding, but I have to say that as a Carer this one statement rang so many bells for me, that there were times I could have listened better and been able to offer better *'quality listening.'* I have realised that this is something the Teams could work on with families and friends of people with mental health difficulties.

## **Ron Collier (April 2008) Research Consultant**

### **Why I became involved in this particular research project?**

The most significant outcome of my research degree experience was recognising that the most effective form of research for social change should be undertaken by those with an investment in bringing about change. The second was realising that those involved with effective change need to be prepared to change as well! This drew me to involvement as research associate with the user researchers on the PINE Project (service users providing a significant educational input in the classroom to student mental health nurses).

I worked alongside Becky Shaw, who was lead researcher on that project, and it was she who asked me to provide an associate input to this new project in Nottingham University's Division of Psychiatry. This is a collaborative project that also involves psychiatrists. I see this as a further opportunity for professionals and service users to extend their areas of common ground in the understanding and treatment of mental illness.

## **Pat Massie (2008) Mental Health Carer Interviewer**

### **Why did I become involved in research?**

I initially became involved with the mental health services 13 years ago when my husband was diagnosed with schizophrenia. Fortunately, he improved on his medication, and after several months was able to return to temporary work. At this stage the only contact was with the GP, and this was soon dropped, as he just got his repeat prescriptions. He couldn't manage to find regular work, I worked to keep us, and although I had learned something about mental illness, neither of us were involved in any way with any type of group.

I then heard about Linking Voices, and joined when they came into being. This led to a number of training courses and of course East Forum and Strategy group meetings. I became involved in research because mental illness was a complete mystery to me, despite 'going on line'. I find it useful to try to understand other peoples' experience, and feel that family members should try to understand the problems experienced by service users.

## **Michael Osborne (2008) Mental Health Service User Researcher**

### **Why did I become involved in research?**

I can't say that I became involved in research for any commitment to its purposes. I became involved because I am so passionate about the welfare of service users that anything which could improve their situation is meat and drink to me. I found that research can have such an impact on improvement of services that I was pleased that I had become interested. It has led to a need for further work in research.

### **Why did I become involved in this particular research project?**

Because it was there and I was asked. I will join anything that can improve the lot of service users. I could see so much benefit from this line of research that I wanted to be a part of it. I have seen some of the results and think that it will be very beneficial. I must also say that I have learned a lot for which I'm truly grateful to the team. I have also enjoyed myself. A win/win situation all round accepting that my contribution was regarded as useful!

The experience of living with mental health difficulties is a bit like a rollercoaster, some days are better than others. I had not realised that you could recover and live with these ups and downs and with these difficulties but manage them in a way that meant I could still live a fulfilling life like I do today.

## **Nick Panasiw (2009) Mental Health Service User Researcher**

My involvement in the CRHT research project came as a result of involvement with a Carer Users' forum in Lincolnshire, which was going to undertake a similar piece of work.

This research project merged with the CRHT study being undertaken by Rebecca Shaw, Brian Ferguson and Hugh Middleton in Nottinghamshire and Lincolnshire. The experience of being part of the research as someone who had very little research experience of this type has been beneficial to me personally, making a contribution, feeling useful and gaining confidence in my abilities. More important than any personal sense of wellbeing, is the small part I played in the success of this study.

The interviewing of users of the services was very educational, the privilege of interviewing a wide range of people has deepened my empathy with the many difficulties, people who use services suffer, and consequently the importance of having a really good CRHT service.

## **John Tear (2009) Mental Health Service User Researcher**

At the time this project commenced I was chairman of the South West Forum of Linking Voices, a Service User and Carer focus monitoring group in Lincolnshire. A recurrent theme at all our meetings was what was happening with the Crisis Teams. Not a month would go by without someone raising the subject and relating their experiences. Whether the system was failing or whether service users' expectations were unrealistic the situation was unsatisfactory and it was evident that some action was needed. Therefore, when the opportunity arose to participate in this joint research undertaken between Lincolnshire and Nottinghamshire, I jumped at the chance to be part of it. There followed some intensive training sessions, learning interview techniques and preparing questions as well as equipping us for the individual roles we would play, this also proved to be a useful group bonding exercise. You learnt a lot about others and you gained strength from this. I think those being interviewed certainly appreciated knowing that we were also were or are fellow service users and I am sure this is reflected itself in the openness and detailed answers freely given. Personally I was especially interested in how each individual described their own journey through crisis. As to the analysis and outcome, what was most noticeable to me was how wide ranging these experiences were. They varied from one extreme to the other, some felt badly let down, whilst others felt their lives transformed from despair to hope I think this enterprise fully justified itself and we can all learn lessons from it, moreover it shows how the services can be improved. My own viewpoint is that we have to balance a standard service to everyone with the need to provide each individual with their own plan. Finally I would like to thank my colleagues, both service users and professionals for the encouragement they gave me. As well as finding new friends I myself have certainly grown in confidence through taking part in this project and would welcome the prospect of being involved in any future research work.



# **Becky Shaw (2008) Mental Health Service User Researcher and Trainer**

## **Why did I become involved in research?**

As I started to recover and regain my strength and will to have a future after years of struggling with my mental health, I started to challenge the very system that had been trying to help me. I knew through my experiences of using the mental health system that things were not working in the way that they should. A mental health acute ward should be a positive, relaxing and therapeutic place and services should be based on the needs of the people who use them. I know that many people who use the services say this is not the case and I can only speak from my experience that for me this was not the case too. I was angry for a long time about the way in which I was treated and the lack of respect my opinion about my treatment was given. I could not stay angry as that does not change anything but how could I facilitate change?

I fell back into research, I suppose, by accident. I would not wish mental health distress on anyone, but it has given me a passion to help change the mental health services for the better, to empower change through education and research and in the end just be a small part of a piece in the puzzle that helps the cogs to just work that little bit better for the people that use them including myself.

Over the last eight years progress has been slow and although there is a government directive to involve service users in healthcare this at first was only at a token level.

## **Why did I become involved in this particular research project?**

After completing a piece of research on people who had used the mental health services being trained to deliver teaching sessions I decided to do more as it proved beneficial to me and others. I became involved in the following research study after talking with other people who had also used the Crisis Resolution and Home Treatment Service for Mental Health Care. I realised that there was a need to research the area of crisis support. Were my experiences and those I had spoken too a realistic picture of the service?

I have led this research which is a collaboration between people who use the mental health services, carers, psychiatrists and other professionals. Having a great mix of people and expertise that they all bring means this project is coming to life and to its full potential.

## **The Research Team**

- Becky Shaw                      Chief Investigator
- Dr Brian Ferguson            Principal Investigator
- Dr Hugh Middleton           Principal Investigator

## **Core Research Group**

The core research group has been made up of people from all those mentioned here.

Membership of this group has varied depending on the purpose of the work identified.

Individuals have attended as and when needed according to their skills and interests.

- **East Midlands Mental Health Research Network (MHRN)**

Ann Priddey	Claire Broomhead	Florence Grindlay
Roy McPartland	Sandra Creasey	Joanne Greenwood

- **AMAZE Team Members (analysis group):**

Adan Walker	John Tear	Angela Smith	Michael Osborne
Becky Shaw	Rosemary Wilson	Chris Heap	Peter Robinson
Johanna Sharland	Val Stapleton	Nick Panasiw	Gregory James

- **Service User & Carer Interviewers**

Adan Walker	John Tear	Angela Smith	Nick Panasiw
Becky Shaw	John Welsh	Chris Heap	Michael Osborne
Chris Ridgwell	Robin Fryatt	David Barker	Rosemary Wilson
Gregory James	Pat Massie	Hugh Thomas	Peter Robinson
Johanna Sharland	Val Stapleton		

- **Other members of the Research Team**

Dr Ron Collier - Research Consultant

Amy Purser - Social Scientist

Gill Thompson	Michael Worth	Jean Sharp
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# Useful Contacts

## **AMAZE research team**

We are a group of trained researchers who have experience of using the mental health services or who have looked after someone (i.e. a carer). Our main focus is qualitative research. If you have a piece of research that needs undertaking or you need interviewers with experience such as ourselves then do please contact us. If we are unable to help we often know other groups and individuals who can.

Co: 4 Holme Road, Bingham, Nottinghamshire, NG13 8DZ

[bshawmh@inbox.com](mailto:bshawmh@inbox.com)

## **The Rushcliffe Mental Health Support Group**

A long running peer support group set up to provide support for those affected by mental health difficulties in Nottinghamshire. The group works with other local and national mental health groups and organisations in order to raise mental health awareness, provide training and offer peer support. Publications are available to purchase through the website below all profits are going back into the group to continue their work.

[WWW.mentalation.co.uk](http://WWW.mentalation.co.uk)

## **Dr Ron Collier (research consultant)**

Providing support in social research

-particularity insider research and issues of social justice

[ron.collier@tisacli.co.uk](mailto:ron.collier@tisacli.co.uk)

## **Dr Brian Ferguson and Dr Hugh Middleton**

Both can be initially contacted via the AMaze email or address

## **References**

Collier, Ron (2010) Making Sense of Schools and Community Divisions - Towards a Definition of Social Reality: *Eloquent books, Durham, Conneticut*

## **Books that may also be of interest**

Shaw, Becky (2009) Wonderfully Strange: *publisher Rebecca Shaw in conjunction with Writersworld*

Rushcliffe Mental Health Support Group Shaw, B and Thomas, H (2009) Discovering Recovery: *publisher Ruscliffe support Group in conjunction with Writiersworld*

Cupitt, C (2010) reaching out - the psychology of assertive outreach: *Routledge*

## **Mental Health Research Network**

Since its inception in 2004, the East Midlands Mental Health Research Network Hub (MHRN) has developed into a very effective organisation providing support to a wide range of nationally accredited NIHR portfolio studies in mental health. In 2009 it was foremost among Topic Specific Mental Health Hubs in the United Kingdom with the highest number of participants in portfolio studies. More recently, an exciting new partnership has been established with South Yorkshire Comprehensive Local Research Network (CLRN) bringing together for the first time researchers, service users and carers from the counties of Derbyshire, Lincolnshire, Nottinghamshire and South Yorkshire, culminating in a change of name to “East Midlands MHRN in partnership with South Yorkshire CLRN” (EM & SY MHRN).

The Hub is hosted by Nottinghamshire Healthcare NHS Trust (NHCT) and the partnership employs Clinical Studies Officers (CSOs) whose job it is to work with clinicians and researchers to assist with recruitment to portfolio studies.

The Hub has a lively Patient and Public Involvement Group who meet every 6 weeks. Guest speakers lead debate and discussion. The group also bid for national pieces of work to Service Users in Research, the PPI arm of the MHRN and have successfully held focus groups to recommend changes to the national guidelines for involvement. The group supported the CRHT study and continue to support service users, carers, patients and the public to be involved in research from the design stage to recruitment.

The Hub can be contacted by emailing Ann Priddey, EM&SY MHRN Research Network Manager

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