

## **Report on service user involvement and recovery projects**

In 2007, after several meetings between Martin Koball (service user consultant co-ordinator) and members of South Shrewsbury Community Mental Health Team (CMHT) and Social Inclusion and Recovery Service (SIRS), and discussions within these teams, an advert was put up in the CMHT waiting room to initiate a more coherent way of linking service user and staff expertise in terms of what happens in these teams:

### **Can you help?**

We are looking for someone to act as a *service-user consultant* to help Tim Childs (South Shrewsbury CMHT manger), Guy Holmes (CMHT Psychologist) and Paul Eaton (Social Inclusion and Recovery Service) identify and put in place ways of getting feedback from people who come to the CMHT. For example, this might include different ways of getting information about what is done well, what is done poorly, how things could be improved, how people might work together to assist recovery from problems.

A payment of £20 per session is payable (this does not affect any benefits someone might receive)

If you are interested and want to find out more please speak to the secretaries or contact Tim: 01743 254050 or by email:

[tim.childs@shropshire-cc.gov.uk](mailto:tim.childs@shropshire-cc.gov.uk)

Three people responded to this ad – Jennie Brazier, Annette Goodhall and Alastair Jones - and the six of us met to discuss service user involvement in the team, how to get feedback to staff members, the pros and cons of using questionnaires regarding people's satisfaction regarding the services, how to get people more involved in shaping the services they receive, etc. The more we explored things, and tried to tackle the complexities of these issues, the more there appeared to be a consensus around the need to debate and explore the area that has come to be known as 'recovery.' We decided to organise an afternoon event to which everybody involved in South Shrewsbury CMHT and SIRS (whether providing or receiving a service) would be invited (see page 2 to see a copy of the poster that advertised this event).

26 people attended the event, 15 speaking from a service user perspective, 2 as carers, 1 as a carer supporter, 7 as members of the CMHT/SIRS and one G.P. counsellor. People engaged in a wide-ranging debate about the notion of recovery, spoke passionately about the local services, and made many constructive criticisms and suggestions for change. There was a lot of discussion about the merits of having more people who receive a service having an involvement in the services in terms of how they are run. Graffiti boards were set up for people to record their views about recovery, the CMHT and SIRS service and the day in general. We agreed to write up the comments that people made on the graffiti boards in the form of a report or bulletin to be sent to everyone involved in South Shrewsbury CMHT and the Social Inclusion and Recovery Service. It is hoped that this will assist more debate and reflection on the concept of

recovery from people who provide and receive services, and lead to projects and changes in services where appropriate.

.....joining a footy club..... realising no-one else is going to get me better....meditation.....getting meaningful work....shopping.....mentoring.....healing....bowls....being left alone-I'm alright the way I am....accessing education.....supportive friends...therapies..... belonging to a church or other spiritual organisation....freeing myself from services....being left to live life the way I think best.....having sufficient money and power to make life-changing decisions... smoking... medication... taking responsibility for my own life...

# "Recovery"

What do mental health workers mean when they talk of *recovery*?

What has helped you to 'recover'?

What do people recover from...their illness or mental health problem?...a breakdown?...a trauma?...their treatment from services?...from poverty?

Is recovery a word used to cover the fact that services are being cut or people can no longer get things for free?

Is recovery just another buzzword...like 'empowerment'...with very little meaning and very little actually changing?

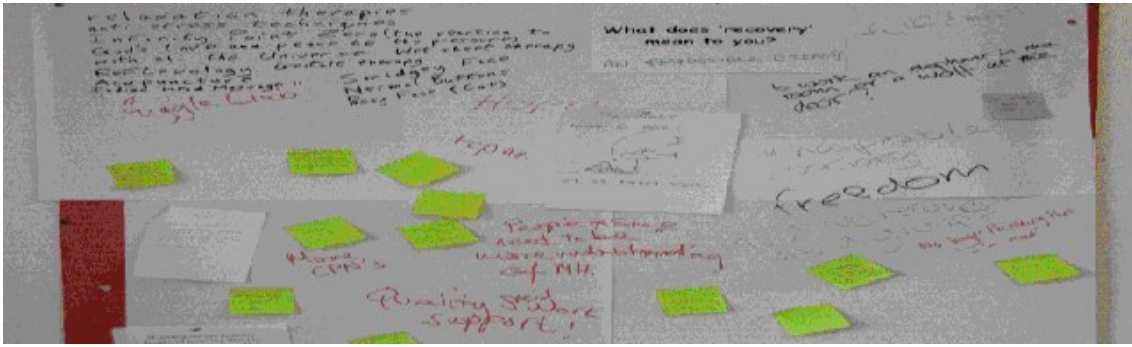
What needs to happen in local services and in the south Shrewsbury area to help people really *recover*?

Annette Goodhall, Alastair Jones, Jenny Brazier, Paul Eaton, Tim Childs and Guy Holmes have started meeting to discuss these and other related issues concerning 'recovery.' Why not join them, add to the debate and have an influence on how South Shrewsbury CMHT and the Social Inclusion and Recovery Service operate in ways that might help people to *recover*?

The meetings are open to everyone – people who attend local mental health services.....relatives....friends....staff.....anyone who is interested

***Come along, listen to the debate, have your say  
and see if we can bring about some change***

Comments were made on graffiti boards on several different topics (see pic on p.3 and comments recorded under the following headings 1-6). These were collected at the end of the day and are reproduced here in full without any editing.



# 1. What is 'Recovery'? What does recovery mean to you?

Some people tried to encapsulate this in a single word:

*Acceptance; Clearance; Fulfilment; Freedom; Hope; Repair*

Others in a short phrase:

*An hospitable society; Knowing I'm ok; Taking small steps towards my current goal; No longer thinking that "I'm mad"; Building up self-esteem and confidence; Learning to take responsibility for oneself and actions in day to day life; To find contentment as near as possible; To be able to be positive and optimistic; To find a more relaxed and less troublesome existence*

Some people asked fundamental questions about the concept:

*Is work an elephant in the room or a wolf at the door?  
Must we recover as a group?  
An impossible dream?*

Some people attempted a definition:

*"Being able to lead as much a satisfying life as possible amidst the difficulties poor mental health can bring"*

*"Recovering the rights and responsibilities lost, stolen +/-or surrendered as a result of a mental health episode"*

*"Infinity point zero (the reaction to God's love and peace be the pressure) with all the universe, Smidgy Face Normal buttons Pussy face (cat)"*

*"Persevering through and adapting daily to what you feel you are able or not able to do without giving up totally"*

One person tried to encapsulate 'Recovery' in a drawing – the moon, a rocket, a helicopter engaged in rescuing moonmen from the sea, accompanied by the phrase "What is recovery: RECOVERY OF PEOPLE – IT IS ROCKET SCIENCE"

Some tried to encapsulate recovery in a poem:

Have you ever heard an angel fly?  
Does it move quickly through the sky?  
Is there a noise as its wings unfold?  
A rush of air? That's what I'm told!  
A heavy body, tough, heavenly  
A heart so light, so full of glee  
To spread God's word and dispel fear  
For those who want or need to hear  
I did, I did, I heard one once  
And saw the framework from which it comest  
From fright and honour I could not look  
But only listen to the path it took  
And if again I heed its call  
I wonder if I shall look at all  
Or speak or listen to what does say  
To know of love's external day

One person defined it in practical terms:

*"I would like to be able to feel comfortable doing everyday things e.g. going to the bank, shopping etc. Just being able to go on familiar bus routes etc. Would also like to come off all medication in the future."*

Others brought in definitions from people they perhaps admired:

*"We must become confident in our own abilities to change our lives; we must give up being reliant on others doing everything for us. We need to start doing these things for ourselves. We must have the confidence to give up being ill so that we can start being recovered. We must work at raising our self esteem by becoming citizens within our own communities despite our communities if need be. We are valued members of our societies and we must recognise our value. We need to recognise our own faults - the system may have created our diagnoses, but often it is ourselves who reinforce it. We need to change these behaviours that still trap us in our roles as patients. We need to accept and be proud of who and what we are; I can honestly say my name is Ron Coleman and I am psychotic and proud. This is not a flippant statement; this is a statement of fact." (Ron Coleman – Recovery: An Alien Concept).*

*"If people are the building blocks of recovery then the cornerstone must be self. I believe without reservation that the biggest hurdle we face on our journey to recovery is ourselves. Recovery requires self-confidence, self-esteem, self-awareness and self-acceptance; without this recovery is not worth it." (Ron Coleman – Recovery: An Alien Concept)*

*"Recovery requires the right atmosphere or organizational climate in your mental health organization - one that is sensitive to consumers and values independence of the individual. It allows consumers to risk, to fail. It holds that every consumer has a right to the same pleasures, passions, and pursuits of happiness that we have. It looks at potential, not deficits." (Weaver, 1998)*

## **2. What has helped you to Recover?**

People listed a wide variety of things. Some comments seemed to relate to services (in the statutory and voluntary sector) and service user involvement:

*Observer House and SIRS staff. Always having someone to talk to and a place to be yourself, even on a bad day. Displaces the isolation and gives my internal thoughts and worries a voice, outside of going round and round in my mind*

*Having the same psychiatrist for a number of years*

*Contacts for support*

*Small achievable goals, but worked towards with support from mental health team – having someone who will listen*

*“Giggle club”*

*Relaxation therapies; Anti-stress techniques; Wet sheet therapy; Reflexology; Gestalt therapy; Acupuncture; Indian Head Massage*

*Continuity courses on anxiety management & building up self-confidence*

**CARDIAC REHAB TEAM!**

*Being part of an activity group for service users*

*Service user involvement has improved self esteem, confidence, capacity to think and do more than one thing at a time – increased my mental speed that slowed down due to my illness*

Other comments were more general:

*Seeing things as they really are... some professionals have helped me too*

*Reading fictional books before I sleep switches my mind from negative and repetitive thoughts and worries to another world separate from thinking on my own problems*

*Making sense of my “madness” and coming to see it as not “mad” – talking this through with therapists and non-professionals helped me get there*

*Having the message of getting well, recovering, normalizing, keeping well, feeling good, being in control, being safe, enjoy life, relaxing, sensible*

*La la la la la la, La la la la la la, La la la la la la,  
La la la la la la, La la la la la la, La la la la la la,  
Spread a little happiness as you go by, please try*

*Developing as broad a support base as possible*

*There's always someone worse off than yourself*

*Recovery seems to start when you feel supported, listened to and believed. Then you can begin to believe in yourself*

*Happiness*

*Peace*

*Bountiful – earning – benefit*

*Friends* 

### **3. What has hindered your recovery?**

Again, some comments related to services:

*Lack of funding at government and local level; Being pushed through a system – not listened to; Lack of time to “talk” to professionals; Changes in staff / frequent absences; All the time spent pondering over my illness – staring at 4 walls; A great gap between this and services on offer*

Whilst others were more general:

*My own lack of confidence; Stress; Losing my faith in God; Hostility of previous colleagues – or distancing at least; Being out of work for so long; No one really understands what my requirements are*

One person wrote a poem:

As soon as I am right, I am wrong  
As soon as I am wrong, I am right  
As soon as I see, I am blind  
As soon as I am blind, then I see  
As soon as I feel, I am numb  
As soon as I am numb, then I feel  
As soon as I hear, I am deaf  
As soon as I am deaf, I hear  
As soon as I hear, I am heard  
As soon as I am heard then I hear

### **4. What needs to happen in the CMHT & SIRS to help people recover?**

Some people wrote about changes in philosophies and ways of generally doing things:

*A common understanding of the meaning of “recovery” across both teams*

*Should responsibility for encouraging / promoting ‘recovery’ be hived off to a team?  
Isn't it partly the role of all MH workers?*

*Regular dialogue (including providers & users) aimed at shaping a constantly evolving service*

*A simple step in the right direction is to ask what individuals would like to receive from the service. A forum such as this is helpful for starters*

*Talk to us! Explain things!*

*This is the first time anyone has ever asked us (the service users) for our views. I think it deplorable and smacks a little of arrogance that we are never consulted. It would be more productive for both users and management if we were actively engaged, instead of seemingly being broken down upon. There are so many other areas that need to be opened up and discussed. Also, no information is ever disseminated to service users, as if we are instead to be controlled rather than deciding for ourselves. I don't wish that – tell me what is available and I shall decide for myself. This probably comes from certain attitudes that exist within SIRS which are allowed to go unchallenged*

*Ask not what service providers can do for you, ask what you can do for service providers*

*Take account of carer's views*

*Get rid of the terms service users & service providers. Replace with patients (or should that be patience?) + HELP!*

*Service users have loads of passion – passion is what is needed to bring about change in services and wider in society – tap it!*

*Other people made specific suggestions for additional services or changes to existing services:*

- *Repaint the waiting room area to maybe cream or apricot (lighter colours)*
- *Include some artwork*
- *Update the posters*
- *Maybe have a rug*
  - *Make it more welcoming and help to calm nerves a little*

*Offering holistic therapies – like aromatherapy massage. It really works (Getting it on direct payments is so long winded)*

*Family work!*

*Training at all levels*

*More information given out about mental health services*

*A cup of tea and a chat is not good enough any more*

*SIRS activities*

*Get to know people's hopes and dreams*

*Not change Care Coordinators from CMHT staff to the SIRS staff*

*People and staff need to be more understanding of MH*

*More CPNs*

*Quality social work support!*

*Get rid of social workers and put money in service for more psychologists. That's a part answer*

*Replace the bulk of medication and the so-called help to recover provided by the services with a massive induction of psychotherapists and psychologists*

*Shouldn't be cutting back on support, because that's when people can become ill – because there's not enough support. Someone to listen to you. Stop you from relapsing*

## **5. What needs to happen in the general South Shrewsbury area to help people recover?**

*Bring back the wonderful services that were provided here; aromatherapy, yoga, reflexology but above all the meeting facility that was provided for coffee, tea, music, guitar playing, reading, relaxation – an opportunity to meet and just chat or lie back and relax ... gone forever it would seem?*

*Community-wide action to combat stigma (services for the “mentally ill” often increase it, especially when they segregate and label people)*

*Meaningful jobs that pay £15.00 per hour at least*

*What are the provisions for the over 65s? Where are the support systems? What medical care is available?*

*More support groups around Shrewsbury, like Acorns Giggle Group. We need lots of groups because people need different choices*

*Recovery can't be hived off as the separate responsibility of community services. It should be the focus of MH services as a whole, including inpatient services*

When you recover, From some bother  
Then you smother, Your baby brother  
With a cover, Of lovely plover  
Tis' another, Type of lover  
That lasts forever, And ever Amen  
So let it be, Till eternity

## **6. General comments and what next?**

*Today has been an excellent idea*

*Could identify with a lot of what people said and you feel less alone. Very enjoyable and thought provoking.*

*People seemed able to 'speak their mind' even in the large group debate*

*The concept of recovery challenges the current status quo which subscribes to a largely medical view of what constitutes mental health or illness*

*Have a nice day (accompanied by a sketch of a home)*

*Draw conclusions from abstract to concrete. Recovery together. Recovery indicators  
What can we do?*

*Enjoyed it. Good to hear other people's comments and can see there are a lot of us in the same boat. Let's have a lot more event such as this!*

*Continued discussions (with other team members)*

*Whilst this is the "R" in Recovery (SIRS), I feel there is a danger over becoming over-indulgent in exploring this in any great depth. More, that the service should take us (hopefully) to a state where we are less troubled, if not more relaxed. Otherwise, if it is just a talking-shop and does not progress anymore, then the question should be regarded as redundant (if not retrograde, in so much as it might help instil feelings of institutionalisation). Also would be wasting taxpayers money. If discussed, then only on the simplest level, otherwise we'll disappear up each others derriere, if indulged so*

Hope springs eternal in the human breast;  
Man never Is, but always To be blest:  
The soul, uneasy and confin'd from home,  
Rests and expatiates in a life to come.

-Alexander Pope,  
*An Essay on Man, Epistle I, 1733*

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