



scottishdevelopmentcentre
for mental health

Would Recovery Work in Scotland?

Report of a one day workshop at the West Park Centre, Dundee

13th November 2002



Working to Recovery



This workshop was supported by: Well? National Programme for Improving Mental Health and Well-Being, Scottish Executive.



SCOTTISH EXECUTIVE

Contents	Page
Recovery	3
Recovery workshop	3
Presentations: What is Recovery?	4
Themes from group discussions	6
Ways ahead	12
Postscript	13
Appendix A Open space events	14
Appendix B Open space issues	15
Appendix C Programme	16

This report is based on ideas from all those who came to the workshop on recovery and who contributed their ideas, energy and enthusiasm to the day.

The workshop was coordinated and facilitated by the Scottish Development Centre for Mental Health in collaboration with: Working to Recovery, SAMH, SHS Trust, Penumbra, NSF Scotland, and the Center for Psychiatric Rehabilitation, Boston University. It was supported by Well? National Programme for Improving Mental Health and Wellbeing, Scottish Executive.

Recovery

Recovery is a new idea in mental health in Scotland. For us, the concept of recovery involves enabling individuals to take charge of their own lives with the support which they require. It is about empowering people to make real choices for themselves.

The ideas and principles of recovery are relatively well established in other parts of the world and are gaining increasing currency in the UK. The idea of establishing a Scottish Recovery Forum was first proposed at the Visions and Voices II conference in June 2002. The response to this was very positive and encouraged us to hold the workshop on recovery in November 2002, to give us the opportunity to discuss in Scotland how recovery can shape the way we think about mental health problems and how people can find hope and regain control of their lives.

Recovery workshop

The workshop set out to explore the many different ways of thinking about recovery, recognising that we can all become experts in recovery ourselves. One hundred and seventeen people attended on the day, with 35 people attending as individuals, 34 from statutory agencies, 35 from voluntary organisations and 13 speakers or facilitators. People came from all over Scotland, with rural and remote, urban and island communities all represented. Those attending included:

- People who use services
- Carers and relatives
- Social work staff and social work managers
- Nursing staff and nursing managers
- Advocacy staff
- Support workers
- Policy officers, involvement and development officers
- Chief executives and fundraisers
- Researchers
- Psychologists and psychiatrists
- Art therapists and psychotherapists.

Presentations: What is recovery?

Gregor Henderson

The Scottish Executive National Programme on mental health and well being improvement is pleased to be able to support the first national workshop on Recovery in Scotland and is looking forward to hearing the ideas that come out of the workshop discussions and the recommendations for action to emerge.

This workshop is about supporting existing work on recovery and starting new work to build good practice. The workshop is designed to be grounded in people's real lives to explore what recovery means.

Recovery is both a vision for the future and a social movement that seeks to bring about change in how we think about mental health problems, how we live with those experiences and how we support people whose lives are affected by mental health problems.

Christine Gayler

Recovery is a common human experience: we all experience recovery at some points in our lives. It is a process of transformation, discovery and renewal. Christine and colleagues are working to promote recovery and the development of recovery focused services, for people who have long term, serious mental health problems. This means helping people to recover from the effects of mental health problems, the effects of the mental health system and the effects of the lack of opportunities to work, learn and develop as individuals.

Recovery is about helping people rebuild connections: with themselves and their hopes and dreams, with other people and with the things they want for their lives. A lot of experience and research has been accumulated by those promoting recovery, which points to the impact it has on the lives of people with experience of mental health problems and of people who provide services.

The vision for recovery would be to organise mental health services around the goal of recovery for all people affected by mental health problems. To ensure that recovery can work in Scotland, we need to:

- support the development of services and interventions that are recovery focused
- nurture the development of recovery focused workers
- nurture the process of recovery for people with experience of mental health problems.

We should not underestimate what each of us can contribute to this!

Audrey Reid

Audrey described her experiences of being diagnosed and treated and the effects that her medication had on her ability to work and to study. She came to feel that she no longer wanted to live under the shadow of medication. She felt she had been 'written off' and was depressed - 'who wouldn't be?'

Being part of self-help groups and the Hearing Voices Network was a liberating experience and the start of a journey towards recovery. A key step in this was the decision to reduce and then come off medication.

Recovery involves each person working out for themselves what they need to recover from and how they want to do this. For Audrey, recovering is about 'living with madness and getting your life back, so that you can think again and feel again.' It is important to believe that recovery is possible. It is hard to recover from 'schizophrenia' when you do not know what that means, but you can recover from panic and fear, or from the effects of hearing voices.

Ron Coleman

Recovery is about people being able to function well enough to do the things they want in life. It is an individual process. You have to learn to love and accept yourself to be able to recover. Hold on to your dreams!

People need to recover from the system, not their mental health problem. What has gone wrong with the system, when we know that staff choose mental health work because they want to help and to make a difference? Professionals can choose to be turning points for the people they work with, by putting the person at the centre of the process.

We know from international studies that people in different places and different parts of the world have different chances of recovery, depending on the sort of society or community they live in. We should be asking: 'am I going to accept my responsibility as a user or as a worker to promote recovery?'

Themes from group discussions

Introduction

There were two sets of discussion groups. In the morning, groups discussed the question 'what does recovery have to do with me?' while the afternoon groups focused on a range of issues which arose from the 'Open Space' session (see Appendix B.) One striking feature of the groups was how the discussion returned again and again to several key themes, which are outlined below.

The journey and the pace of the journey

The pace of the journey is gradual and the direction is of our own choosing. It is important to acknowledge where we are now and where we are starting from. We need to take time to work through issues and to work at our own pace. This is not a quick fix and will take time to work.

Early support from professionals is invaluable, keeping hope alive until the person is ready to take over the process. A combination of early intervention and being able to choose what we need to support us would be welcome. A reassessment of how staff use their time and how they and we can use paid time to most benefit would be helpful.

Participants saw the journey as including:

- Having hope
- Having something to look forward to
- Growing and taking responsibility
- Knowing a painful process can lead to a good outcome
- Having enough information to value our own experiences
- Getting to a point where we can get our self-respect back – and believe in ourselves as individuals who matter
- Choosing a future
- Being able to pursue the goals in life that we have defined for ourselves.

Acceptance

Participants underlined the importance of accepting ourselves and where we are:

- Accepting my own failings, that I had a problem
- Accepting what I could or couldn't do
- Accepting the voices and or the illness
- Accepting disability
- Accepting diversity
- Accepting that it's not my fault if life isn't perfect
- Accepting loss as part of change
- Accepting the responsibility for the choices I make in life.

People want to be accepted both when well and unwell and participants thought that everyone has a right to be valued and nurtured throughout their life. It is important to accept change in other people and to respect their right to find their own way.

Support

Support should be made available on the basis of what a person needs or wants, not because of their diagnosis. It ought to be available for as long as someone wants it. Dependency is healthy and natural and everyone needs support at some time. Participants particularly wanted support to be made available for those times when someone's illness affects or interferes with their day-to-day life. Carers said they could not find early advice and support when they wanted it most.

The person offering support should not take over or make assumptions about what's best for us. We need to find ways of giving people choices, for example, support from one single person if that is what someone wants. Listening is important: problem solving doesn't always work, people will find their own solutions.

Participants also wished support to be more readily available for:

- Young people
- Carers – through the provision of respite care
- Parents with mental illness, who need support at home as an alternative to children going into care, including short term, planned, regular fostering
- People who are or who have been homeless.

Relationships

Discussion centred on the importance of building honest relationships between staff and people using services. Participants saw the quality of a relationship as being the key issue. The types of relationships valued most are those that:

- Enable us to talk about feelings and to trust one another
- Enable us to talk about difficult issues together
- Have the potential to develop and become closer
- Allow us to risk being human with one another and to be ourselves
- Are compassionate and allow mutual respect to develop.

Carers can have a key role in recovery. They have a relationship with the person they care for built on trust, where both the carer and the person they care for can speak about their needs and wishes. But carers' experience of services suggests that confidentiality of information can be used as a barrier to carers' involvement. Carers need to talk about a range of issues such as their emotions, fear of the future, passing on genetic problems, their own process of recovery. There was also discussion about the role of other relatives who are not carers.

The availability of support for staff was seen as being an important element in the development of trusting relationships. Ideas for support included:

- Supporting the lone soldiers within institutions and systems by enabling them to develop awareness of their own needs and build networks of supportive groups and individuals
- Enabling workers to discover more creative ways of helping people – more job satisfaction for staff when working with recovery
- Building up networks of people concerned with recovery and social change.

Valuing stories

Sharing stories of recovery allows us to imagine ourselves also recovering. We need to:

- Reflect on and share our own experience of recovery
- Hear and collect stories of people who have used the system successfully
- Use the media and supply positive stories of recovery
- Celebrate the good things.

Informed choices

People need to know that recovery is possible and that early intervention is important. We should be offered choices about services from the first contact and decisions should be made with us, not for us. Support must be offered to us to enable us to make informed decisions.

If we are to make informed choices, we need information and support. For example, to understand our medication, we require:

- Time spent with us helping us understand our illness
- Information on medication eg
 - What it does
 - Likely length of time it needs to be taken
 - What side-effects can reasonably be expected
- Support to make choices about medication and other alternatives, to make choices when we want to, rather than a psychiatrist saying 'not just yet'.
- Research on users' experiences of withdrawing from medication.

Participants said that medication can make people sleep all the time. People are being refused the opportunity to come off or to reduce medication by GPs or psychiatrists, so they are choosing to come off by themselves.

Identity: recovering it can be painful and lonely

Participants thought that getting to know ourselves again is often a lonely process. We might try to get back to what we were, but then realise that we have changed. We need to reclaim ourselves at the same time as finding out what we have become. We want to:

- Have the confidence to be who we are
- Be stubborn
- Recognise our own skills
- Reclaim a sense of being a member of society, for example, being able to vote
- Accept the positive element to madness – it used to be thought of as divinely inspired
- Refuse to see or treat ourselves as mentally disabled
- Learn ways to handle fear.

Learning to live with emotion

It was felt that mental health awareness is needed in all parts of the health care system, to help people in pain and distress and to counter the effects of service specialisation. Services were seen as not being good at dealing with emotions, with individual professionals finding the pace of their work difficult to live with.

It is important to educate our children about what good mental health is and to encourage them to identify their own coping mechanisms. We can also enhance the role of education in teaching children that their minds and bodies are linked. Scottish role models such as comedy celebrities are needed to show that it is ok to have problems and ok to talk about them:

- Accept that pain is real and that we all feel bad about feeling bad
- Acknowledge that being called names does harm us
- Take responsibility for our own madness in order to own our recovery
- Dispel the myth that we can always be happy.

Finding a new life

Participants saw recovery as being about finding a new life for themselves. This could involve:

- Working out our own ways of coping
- Having friends rather than 'a support network'
- Redefining our values
- Working on our own health and learning ways of managing it
- Becoming aware of which people or places were 'bad' for us, so we can steer clear of them in the future (part of making informed choices).

It was seen as important to acknowledge that people can be terrified into compliance because they are afraid their liberty can be taken away and they have to learn to undo the effects of that experience.

Possible future services

It was felt that inspiration is largely missing in services at present. Access to services should not be dependent on key people in particular roles. We should be able to refer ourselves rather than having to go through our GP to access most services. Person centred services were seen as important, recording a person's aims in life and understanding of what the service will offer from the beginning of contact.

Participants were concerned that the services identified as necessary by people who use them are not always funded by commissioners. How to ensure that commissioners fund the services that organisations want to provide on the basis of what service users say they want? Funding could be offered to enable commissioners to meet up with service users for joint trips to innovative or effective resources with a view to trying these out in different areas.

There was some discussion of the doctor's role within the mental health system - do we have the wrong expectations of doctors? It was felt that our relationships with doctors are 'shrouded in mystery' and we are not helped to understand this. Advocacy projects have found that doctors give more of their time to an individual if an advocate is also present. The initiative 'Critical Psychiatry' in England has an important role in challenging the medical model.

'Recovery buddies' - an independent resource, similar to advocacy projects - were seen as a key to recovery. Their role would be to enable those who were ready to begin to take control of their lives to do so with support and information. 'Buddies' would work with a small number of people at a time to find out what those individuals want in life and what is available.

Services could focus on enabling people to find a new life rather than rebuilding the old one:

- Drop-in centres are a key resource – doing everyday things which are fun, making friends, building confidence
- Getting a home rather than a house – being involved in choosing where to live
- Work, including voluntary work – making a meaningful contribution
- Getting about - living in a rural area means that transport must be taken into account.

Holistic opportunities

Participants focused on the perceived gap between services as they are currently provided and a more holistic approach which would include benefits, services, work, mental well-being, 'the whole picture'. Is this what holism means to you? Is this how you see it relating to recovery?

Participants reported that it is not possible to combine part-time work with the current benefits system. Disability Living Allowance is affected by hospitalisation and can lead to individuals leaving hospital too early. Housing benefit could also be a problem for people considering paid employment.

It was felt that there should be a route back into employment that takes account of these types of difficulty and that the benefits system should be simplified to facilitate a return to work. One course of action seen as valuable was attending part-time courses while on benefits to invest in the future by gaining a qualification and making use of social opportunities offered by colleges and universities. Participants saw social firms and clubhouse transitional employment programmes as offering work-related opportunities.

Being able to contribute

Involvement is a process which it was felt should not be over-formalised. However, being able to influence change, feeling part of the process of decision making, influencing 'top' people were all seen as vital in building up people's confidence and enabling them to play an active, positive part in society. It was seen as important that service users are able to set the agenda and that support is offered to service user groups to facilitate their effectiveness.

Does everyone recover?

There were concerns that not everyone will be able to recover and questions about what the future will hold for them. Participants saw that changes in the mental health system would need to be made for those who might not be able to recover. Particular concerns were expressed about people with personality disorder who are often excluded from mainstream mental health services.

Questions included:

Do we know what personality disorder means?

Should personality disorder be medicalised?

What drugs are best to treat it?

Participants concluded, however, by saying that it is possible to recover, whatever the diagnosis.

Ways Ahead

A number of ideas and suggestions emerged from the concluding discussion at the end of the workshop about how to carry forward the discussions and work to support recovery in Scotland:

For people already committed to recovery

There was strong feeling that we need to be supporting each other to ensure that the enthusiasm and energy from the day's discussions can be sustained and used, when people returned to their own area. It will be important to maintain contact and create opportunity for people to exchange ideas and experiences, connecting the work that is being done locally through a network that links people across Scotland. Practical suggestions included a newsletter, mailouts and further events to keep people in touch. The report from the workshop will be one step in this.

For others who have yet to 'get the message' of recovery

It will be important to find ways to spread the message. This includes identifying key groups whose involvement in the process of recovery is essential, for example psychiatrists. People felt it was essential to have more dialogue with professionals who work with a 'medical model'.

Building on people's experiences

The workshop discussions showed that hearing people's stories of recovery is very powerful. This needs to be happening more, locally as well as nationally, in order to challenge how services work. Finding or creating opportunities for people to tell their stories can be an excellent way of raising awareness and of training staff. Some of the ideas for this were: a book or publication, using arts – based work, supporting local initiatives by establishing a national bursary scheme. Continuing to enable people to get together at meetings and workshops would be another step in this direction.

Learning and development

- Those who are involved in services or who work with services need to be talking more about recovery and hope to influence service planning and development, to change practice and to create staying power
- We need more research, of a different type, that shows how people can manage their own lives with the right sort of supports
- We also need to have more examples to point to, of recovery focused services in Scotland.

Postscript

The organisations that helped make the workshop happen are now looking at what they can do individually and what they can do together, with those who came to the workshop and with others, to take up the ideas that came from the workshop. Initial plans that are being explored include:

- Training events that focus on recovery
- Building a web of contacts to provide support and advice local work on recovery
- Story telling, story sharing: to enable people to express their experiences of recovery
- Linking and sharing information and ideas through local and national networks
- A follow on national workshop early in 2004
- Illustrating what can be done if services take a recovery focus

And there will be other things that have not been thought of yet as well as many things that are happening already that we do not know about.

What is clear is that we all have a place in the process of promoting recovery and hope in mental health in Scotland.

Appendix A Open space events

Open space events have taken place all over the world, with as many as 1200 or as few as 5 people. Everyone is there for a purpose. They choose to come because the theme, issue or question at hand is something they have real passion about. They also come because they saw this gathering as a unique opportunity for connecting with others who are eager to learn about, plan for, and take action in an area that they see as critical to the success of their own interests, the work of their organisations, and/or their relationships with colleagues, customers or suppliers.

Everybody starts by sitting in a circle. The facilitator welcomes them and reminds them of the question for the day. She then outlines 4 principles and the one law of open space:

1. Who ever comes, they are the right people
2. Whenever it starts, it's the right time
3. Whatever happens is the only thing that could have
4. When it's over, it's over

The one law is the law of two feet:

That you, only you, know where you can learn and contribute the most to the work that must take place today. It demands that you use your feet to go where you need to go and do what you need to do. If at any time you find that you are not learning or contributing, you have the right and the responsibility to move...find another breakout session, take a walk but do not waste time.

The facilitator invites anyone into the circle, to grab a marker and paper and write down their burning issue, or question. They then read the issue out and take it to the prepared wall and allocate a time to it.

When everyone has finished people are invited to go to the wall and choose the groups they wish to attend. It is up to the groups to take responsibility to start their sessions and keep to time and then find their next session. Each group needs a scribe to write down the main discussion points and most important their recommendations.

At the end of the sessions everybody returns to the circle to finish the day. A report of the day and the recommendations are sent to all the delegates.

Appendix B Open Space issues from workshop

- 1a How can carers be given support to aid recovery?
- 1b How can we make people see that mental health affects everyone?
- 2a How do services aid recovery?
What are the gaps in support at present?
- 2b How can we empower staff and clients to work together as equals on a joint and informed path to recovery?
Medication – who has their say?
- 3a What are the institutional barriers to recovery?
- 3b How do we achieve citizenship as members of society?
- 4a What about the rights of parents with mental health problems?
- 4b What are the steps necessary to move from being on benefits to full time employment?
How do you recover from the benefits system?
- 5a Training – helping professionals find hope
- 5b How can we support each other so we can help each other?
How can we think less, know more, be well?
- 6a Why are we not encouraged to own our madness?
How do you change the nature of the statutory agencies so that they are not the 'caretakers'?
Who decides when you are dependent?
- 6b How to get a life not services?
- 7a How do we encourage service user involvement without being tokenistic?
How do we help people unused to speaking or being heard to find their voices?
- 7b How can people with personality disorders be helped to recover when they are told they are untreatable and beyond help?
- 8a How can we get out of the 'blame the victim' culture?
- 8b How do we move past a 'them and us' culture?

Appendix C Programme

0900 hours	Registration and Tea/Coffee
1000 hours	Welcome and Introductions from the Chair <i>Gregor Henderson, Programme Director, National Programme for Improving Mental Health & Well-Being, Scottish Executive</i>
1010 hours	What is Recovery? Finding Hope: People's Stories Inspiring Change: Shaping Practice <i>Christine Gayler, Field Associate and Master Trainer, Center for Psychiatric Rehabilitation, Boston University</i> <i>Audrey Reid, Hearing Voices Network</i> <i>Ron Coleman, Independent Trainer/Consultant, Working to Recovery</i>
1110 hours	Tea/Coffee Break
1130 hours	What does Recovery have to do with me? (workshops)
1230 hours	Open Space: Would Recovery Work in Scotland? What would it take? <i>Introduced by Karen Taylor, Independent Trainer/Consultant, Working to Recovery</i>
1300 hours	Lunch
1345 hours	Workshops on issues identified in Open Space (2 x 45 minutes)
1515 hours	Tea/Coffee Break
1530 hours	Market Place
1555 hours	Discussion in Plenary Session: Next Steps
1630 hours	Concluding Comments from Allyson McCollam
1645 hours	Close



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