

Talking about recovery

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**Sharing
experiences
of recovery**

Background

In late 2005, Outside the Box began working with the Scottish Recovery Network (SRN) to support the development of local recovery networks.

The project has 2 purposes. The first is to work alongside and assist the pilot networks. We worked with networks in various locations across Scotland. We have also met with people in national organisations who are supporting an organisation-wide network or building in a recovery focus to their work.

In every place where there has been a network, people have undertaken activities to promote recovery. Also in every area, there are aspects which have been difficult or have been slower than the people involved had hoped.

The second purpose of Outside the Box's work is to learn from the experience of the pilots and produce resource materials which can be used by people in any area when they want to start or develop a network to support recovery.

The other resources are:

- Putting a network together
- Starting from people's lived experience
- Sustaining a recovery network
- A set of posters from a workshop which brought together people from the recovery networks across Scotland.

This booklet draws together the experiences from the local areas of people raising awareness about recovery and creating opportunities for people to share their experiences of recovery. Like the other resources, it also draws on the research and established practice from networks that have helped sustain change in big organisations and from the experience of many social change movements.

The illustrations are by Albi Taylor and come from a workshop with the Black and Ethnic Minority recovery Group in Glasgow. A report from that project will be available shortly.

More information

All the resources developed by Outside the Box are available on the website - www.otbds.org – or by contacting the office (see details at the end).

Other useful resources and sources of further information are available from SRN: www.scottishrecovery.net

Talking about recovery

The earlier resource booklet, *Starting from people's lived experience*, described various ways in which people could share their recovery experiences.

Many of the local recovery networks have found that one of the most positive aspects of their activities has been when people started talking about their own recovery journeys.

Examples of opportunities for people to talk about recovery

These are some of the activities which have happened in local areas across Scotland over the past year or so.

- People talking about the SRN book *Journeys to recovery*, and the other personal stories of recovery gathered by the narrative research project.
- People who have lived experience of mental ill-health talking about recovery and what it means to them in small groups – at drop-ins, resource centres, collective advocacy groups and peer support groups.
- Carers' groups having information sessions or conferences, where someone talked about their experiences of recovery. Sometimes this was someone who was a carer, describing what had changed for their relative and for them. Sometimes it was someone who had been ill talking about their own recovery and the part their family and friends had played in that.
- Staff talking about how they found their practice had changed as part of a training session or at team meetings.
- People who have lived experience of recovery talking to people who work in services as part of a training session.
- People who use a service and people who work there coming together to talk about what recovery means for the people whom that service supports.
- Inviting people from other areas to talk about what they have been doing – for example, as a follow up to the DVDs distributed through SRN or when people met each other at a conference.
- Conferences, where people heard someone talk about their recovery experience.
- Workshops at conferences, where people could talk in a smaller group.
- Having a session about recovery or well-being as part of an event that brought people together for another reason, such as an organisation's Annual Meeting.

- People from different types of services, such as employment support and housing services, hearing about people's experiences of recovery and talking about how they could maybe do more to help.
- People who heard about recovery at an event going home or back to their office and telling the people they knew about what they had heard.
- People putting together a collection of poetry or art that expressed people's experience of recovery.

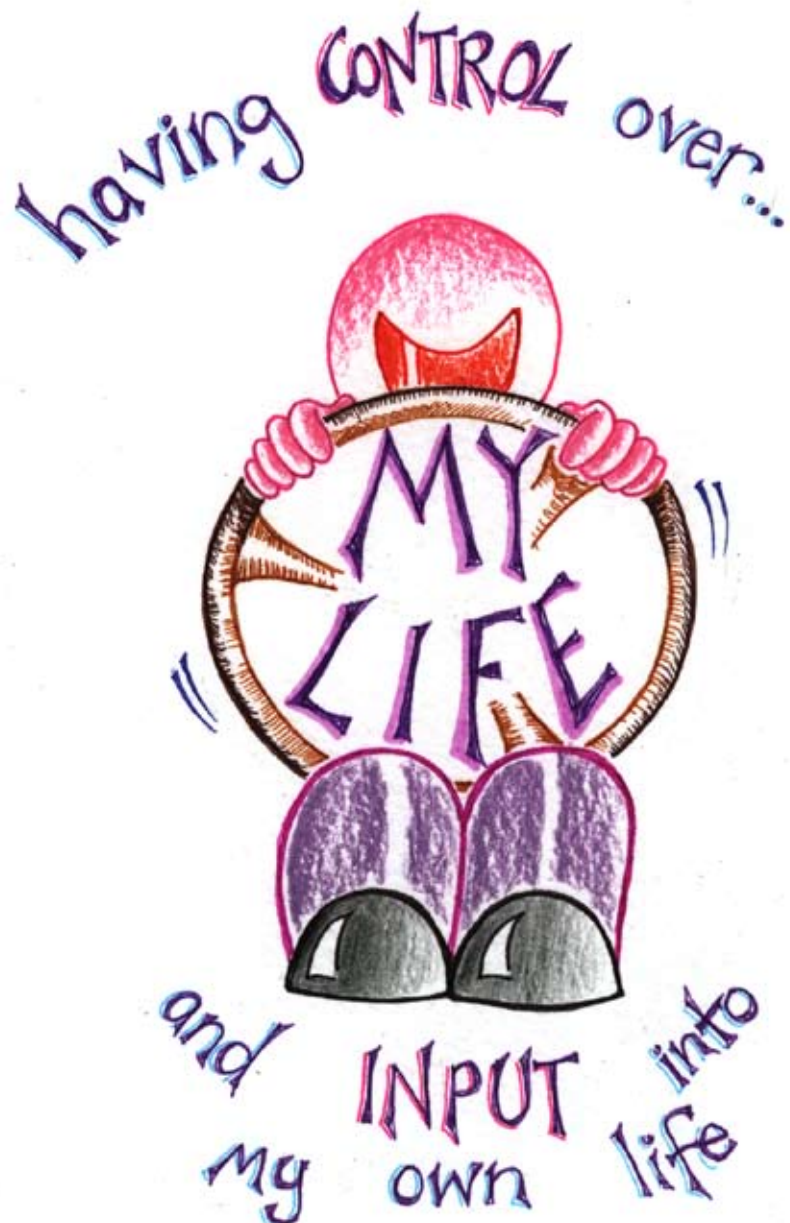
More information

Details of the SRN narrative research project and the personal accounts which have been gathered are on the SER website: www.scottishrecovery.net

Copies of the book *Journeys to recovery* are available from SRN – see contact details at the end.

These are some of the features that help.

- Drawing on the good practice already established for the groups and organisations within the network – such as respecting confidentiality and people taking responsibility for what they say about themselves.
- Having some written material that people can take away with them, with contacts for further information.
- Letting people share their experiences in the ways that are right for them – so through art, poetry or music as well as by talking about recovery.



Stages of change in recovery

“20 years ago I was told I had a life-long illness. I’ve spent my life dealing with that and all the consequences of what I could not do because of it. A new word like recovery is not going to change that for me.”

“I thought this was for other people, not me. Then I read the SRN book with the recovery stories. And I realised that it was possible, that maybe my life had been changing too.”

All the information and material about recovery emphasises that recovery is a very personal experience, a change process that has hope and resilience as its roots. People who live with mental health problems are at different stages in their own awareness of recovery and at different stages of change in their recovery journeys.

All the local recovery networks have been keen to spread the word about recovery. However, the experience of the local networks has been that the responses could vary a lot.

- Sometimes it was more difficult than the people in the local network had expected to have discussions about recovery. An example was when some people in mental health user groups or in places like day hospitals or drop-in groups were not familiar with the ideas around recovery.
- Some people who had mental health problems were not at all keen on these ideas about recovery. For some people, it was hard to get away from the message they had been given when they were first diagnosed with a serious mental illness. Other people associated the ideas around recovery with other changes, such as reductions in some types of services or with a pressure on people with disabilities to get into paid work.
- The local networks found a similar situation when they tried to talk about recovery to some carers’ groups. If anything, they generally found that even fewer of the carers had heard about recovery or believed it was possible.
- They also got a mixed response from people who worked in mental health and other services.
- But the local networks also found people who appreciated what they had done to spread the word about recovery.

Dr Steve Onken lives and works in the USA. He has carried out research and worked alongside many people with lived experience of recovery and with staff working in mental health services in the US and in other countries. Steve talked about the stages of change that are useful in supporting a person’s recovery journey, whether carer, provider or service user, at a series of workshops with local networks in Scotland in June 2006. There is more information from Steve’s presentations on the Outside the Box and Scottish Recovery Network websites.

This chart is based on the ideas Steve discussed with people from the local networks. It focuses on understanding the change process and applying this understanding to personal, organisational or community change (and resistance to change). The people involved thought it was a good way to describe and help them plan how to deal with the reactions they encountered.

How people change – understanding the change process		
Stage	What people are thinking	What helps
Pre-contemplation	<p>I don't even know what this is yet</p> <p>I'm not ready to think about it</p>	<p>Introduce the person to people like them who have moved on a bit</p> <p>Hearing or reading other people's stories</p> <p>Short, gentle background notes to help people understand what recovery might mean, or what other people have said worked for them</p> <p>Focus on the outcomes – what changed for people, what happened to those people</p> <p>Encourage people to think about their experiences and what they want in their life – and do it with a friend they trust rather than in a group setting</p>
Contemplation	<p>Ok, I'm ready to think about it – tell me more</p>	<p>Introduce person to people like them who have done this</p> <p>Short, gentle background notes they can refer to later</p> <p>Share and discuss other people's narratives and writings about recovery</p> <p>Answer their questions</p>
Preparation	<p>I'm getting ready to make a change</p> <p>I can see it's a good idea, but I've got questions about some parts of it</p> <p>I want to recover – how do I do it?</p>	<p>Introduce to people who have done the change, and can say how to do it – process rather than outcome</p> <p>Help with making a plan for this person – help the person identify some things that can be readily changed and some larger goals</p> <p>Introduce the person to recovery planning tools, and help the person apply these to his or her own life</p> <p>Answer this particular set of questions</p>
Action	<p>I'm doing it</p> <p>One small step, then celebrate, another small step, celebrate! Now for a bigger step...</p> <p>If it isn't working, I try another way</p> <p>There are many paths to recovery, mine works for me</p> <p>Some of my best learning came from taking risks and learning from my mistakes</p>	<p>Help and support with achieving the plan – start with things that can be readily changed and build on these successes</p> <p>Access to information, advice and practical resources when needed</p> <p>Encouragement to try something different if current action is not working</p> <p>Support informed risk taking – thinking about the purpose, possible consequences as well as the benefits</p> <p>Mistakes are a normal part of life, now what can be learned from them?</p> <p>Create changes/ opportunities in the community that support a person's action, such as paid, regular jobs</p>

Stage	What people are thinking	What helps
Maintenance	<p>I'm keeping on doing it</p> <p>Keep coming back, it works!</p> <p>I am not the only one here; we can help each other maintain our gains</p> <p>Through helping others, I stay healthier myself</p> <p>Taking care of my cat keeps me responsible for taking care of myself – she needs me</p>	<p>Support, encouragement and practical advice from people who have done it before</p> <p>Celebrate – a day, a week, a new job, etc.</p> <p>Reassurance - Focus on wellness in a holistic sense, and how it is useful for anyone</p> <p>Create and support changes in the organization and community that support a person maintaining his or her gains, for example, a service user run centre</p> <p>Educate and encourage people to use regular community businesses and organizations as supports, such as the local fitness centre – educate these organizations where helpful, such as openness and affirmation within a faith community for their members who are struggling with mental health or are recovering</p> <p>Reminders about what differences it makes</p>
Setbacks	<p>It's harder than I thought</p> <p>I'm feeling discouraged</p> <p>I am still struggling with the episodic nature of my symptoms – why haven't they gone away?</p> <p>As I open up to the recovery process I feel more vulnerable – this is triggering my symptoms</p> <p>I am responding to newly uncovered traumas and hurt by withdrawing and grieving - how can I heal?</p> <p>Is this ok?</p>	<p>Reassurance that setbacks happen</p> <p>Convey resounding hope and absolute belief that the person will pull through and ultimately get better</p> <p>Emphasise that setbacks are not failures, they are a natural part of growth and change</p> <p>Reminding people that setbacks are not the same as stopping – more of a time to take care of self before resuming one's recovery journey</p> <p>Advice and support from people who can help with these particular setbacks</p> <p>Acknowledge that trauma is often a central experience of psychiatric disorder and encourage the consideration and use of trauma healing options and alternatives</p> <p>Reminders about how far they've come</p> <p>Hang in there with the person – support him or her in 'regrouping' efforts and/or in healing efforts, be encouraging and real</p>

More information

The model Dr. Onken shared is an adaptation of the Transtheoretical Model of Change developed by James Prochaska and Carlo DiClemente (1983) with subsequent revisions (Ridgway & Press, 2004) for psychiatric disorders.

Prochaska, J. O., & DiClemente, C. C. (1983). Stages and processes of self-change in smoking: Toward an integrative model of change. *Journal of Consulting & Clinical Psychology*, 51, 390–395.

Ridgway, P.A., & Press, A. (2004). *Assessing the recovery commitment of your mental health service: A user's guide to the Development of recovery enhancing environments measure (DREEM)*. UK pilot version. Wolverhampton UK: University of Wolverhampton, School of Health.

More information

There is a set of posters from the workshop Steve Onken led with people from recovery networks on the Outside the Box website: www.otbds.org

The text notes from Dr Onken's presentations at this and other events sponsored by SRN are on the SRN website: www.scottishrecovery.net

These are some of the activities local networks have done to raise awareness about recovery with people who were not yet actively thinking about recovery – the pre-contemplation stage of change.

- Putting up posters in places like day hospitals, out-patients departments, where people using health services, families and staff would see them.
- Getting posters into places like libraries and post offices.
- Someone who has lived experience of recovery going along and talking to small groups of people in places like day hospitals and drop-ins.
- Having a short session about recovery as part of an information day for carers, with a presentation from someone explaining about her recovery and how her family helped.
- A member of staff getting someone from another area to talk to staff from her professional group about recovery and how they could contribute their particular skills.
- Sending information about recovery and contacts for more information to every service provider in an area.

These are some of the activities which have been helpful for people who are already comfortable about thinking about their recovery – the contemplation stage of change.

- Joint training sessions that brought together people from a range of professions and organisations, based around presentations by people who used those services about what helped their recovery.
- People with lived experience of recovery getting together and talking about what helps them and becoming an additional form of peer support for each other.
- Holding local workshops and conferences about recovery – sometimes with a speaker who is over for SRN events.

Aspects of recovery

The overall experience of the local networks was that it helped to keep talking about all the different aspects of recovery. That way, everyone had the opportunity to become involved in the aspects that mean most to them.

Some local networks found they were concentrating on one aspect of recovery, or one way of supporting recovery: for example, peer support, getting back to work, service users training staff, or nursing staff adopting a particular model of care. Often this was because some people were enthusiastic about that aspect. The advantage was a concentrated effort to learn about and develop skills around that aspect of recovery. But the disadvantage was that people who were not so interested in that aspect could feel that recovery was not relevant to them, or that their experience was not valued.

The chart shows some of the aspects of recovery, and how these link together.

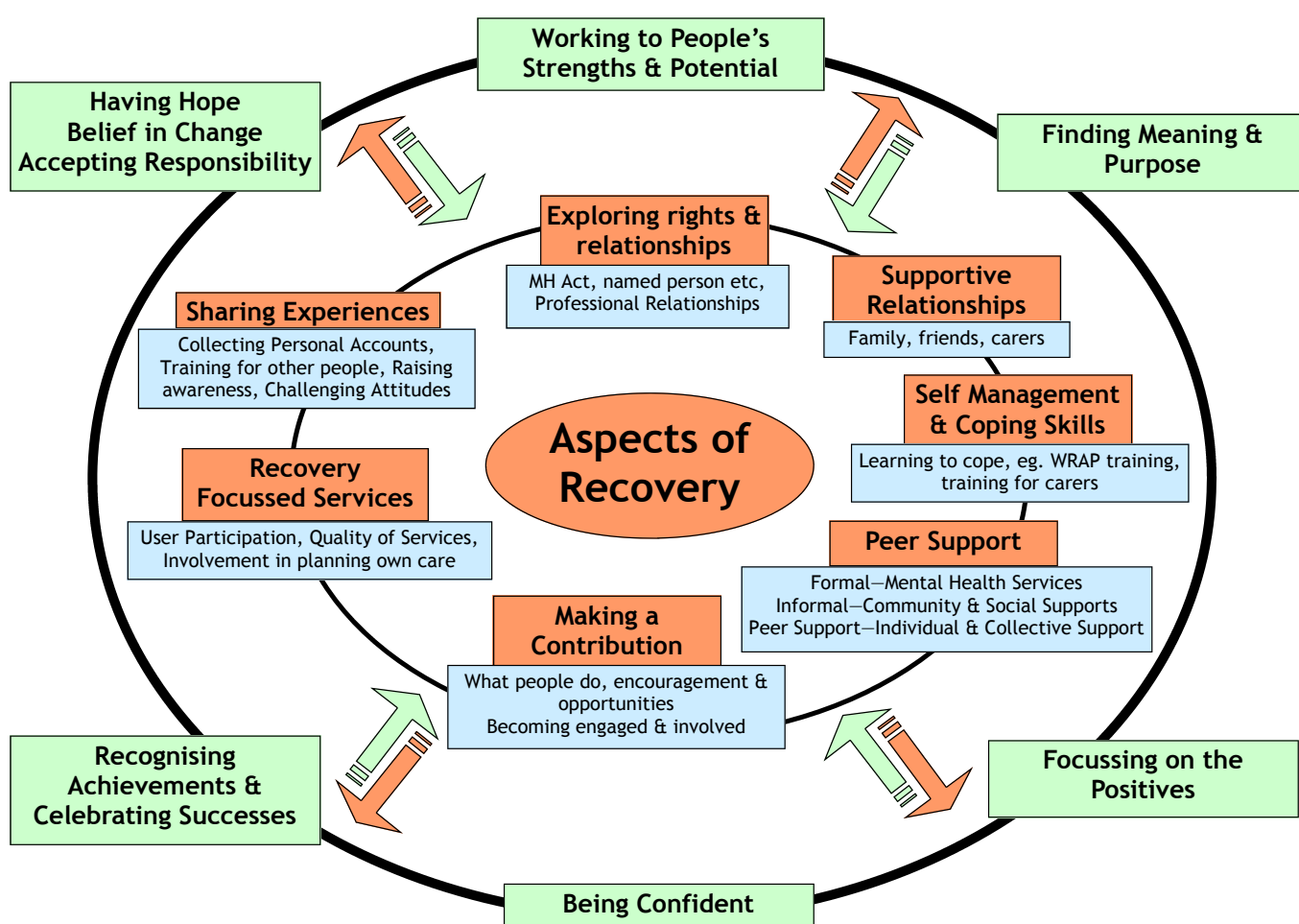
- The green boxes around the outside show the values that underpin every aspect of recovery.
- The brown boxes are some of the aspects of recovery that people have focussed on.
- The blue boxes are some of the features or activities within these aspects of recovery.

A network is a good way of enabling people in an area to get the benefits of putting a lot of effort into an aspect that is important for that place and still having activities on many aspects of recovery. Some people can focus on a particular aspect. But they know that other people in their area are focussing on other aspects. The network helps them keep in touch with each other, and encourages them to come together from time to time to share what they are learning.

These are some of the ways people in a local area can use the chart.

- People have used it as the basis for a discussion in a group of people who use services or carers, to help them think about what recovery means to them and what they want to talk about or do though that group.
- A core group of a recovery network can use the chart to look at where the people in their area are putting their efforts. Are there some aspects which no-one is covering? Are there some aspects where they feel stuck, where some advice from someone outside or another recovery group might be useful?
- People in an organisation which provides services can use it to help them think about what they are doing to make their services recovery-focussed. It can also help everyone understand how their work fits in to other activities with which the people who use their services and staff might be getting involved.

- People who work in services can use it to help them think about how other aspects of recovery are important for individuals in addition to having support from recovery-focused services. It can be a starting point for discussions about how staff in a service can encourage and support people in other aspects of recovery.
- People can use the green boxes as a prompt for reflecting on how the aspects of recovery in which they are most involved reflect the underlying values and the outcomes which all recovery-centred activities are working towards – for individuals, organisations and for networks.



More information

There is a copy of the chart on the website which people can download if they want to make copies.

Keeping the focus on recovery

The focus of the local recovery networks is on people's recovery from mental health problems or their consequences. The experience from many different types of networks is that a strong network keeps the focus on the main interest or issue. The network might get involved in other matters, but the people involved know how these connect to central aim.

The local recovery networks had to find the balance between keeping the network going and contributing to the types of change that members want to see.

The networks found that it helped to slow down what they were planning – get more people involved in the planning stage, have a first meeting and reflect about what next rather than pressing ahead with a series of sessions.

Another useful approach has been to encourage people to get involved in particular activities that interest them, such as planning and running an event, designing a leaflet or gathering a collection of local people's recovery stories.

“At first we felt we had to be doing things, being active and busy. So we weren't taking time to talk about recovery and learn from each other. It fell into place when we realised that the conversation was what mattered. That was the activity.”

These suggestions come from the networks' experience of what helped them to keep the focus on recovery.

- Many people in that area know about recovery and are broadly supportive of it.
- Sharing information about all the activities SRN is supporting. That way, if a few people hear about one particular aspect at an SRN or other event and get very enthusiastic, the other people in the local network know they can stay involved in other aspects too.
- Having lots of conversations about what recovery means for people, what their experiences are, and what their questions and concerns are. The suggestions in Putting a network together and Starting from people's experience are useful.
- Using the ideas from Steve Onken's seminars about the stages in how people change, to help identify what sorts of information about recovery different people need.
- Not rushing – taking time for people to get to know each other, learn about recovery, reflect on their own experiences and hear other people's.
- Keeping the direction of the network open and flexible, so it can respond to what people find helpful and want to contribute.

Sharing the recovery message with the wider community

“People lead their own recovery. Services facilitate recovery. Communities support recovery.”

One of the aims of the Scottish Recovery Network is to raise awareness about recovery with a wide range of people. The local networks have also started sharing the message beyond the people who have links with mental health services.

These are some of the activities which the networks have started to reach members of the public.

- Getting coverage in the local newspapers about events they are running, so people hear about what was said.
- Advertising coming events such as a conference or art show in the local newspaper and encouraging anyone who is interested to come along.
- Putting up posters or leaving leaflets in places where lots of people go – shops, post offices, libraries, community centres, pubs, coffee shops, car boot fairs and more.
- Inviting members of other community groups to come along to events or activities, or offering to come and talk about recovery. Examples of the groups include women’s groups, volunteer projects, tenants’ associations and arts projects.
- Combining fundraising activities and spreading the word about recovery.
- Joint work with a local school, to reach young people.
- Doing community mapping to help think about all the people and groups that have been helpful as part of people’s recovery, and then getting in touch with those people. The booklet Starting from people’s lived experience has notes on how to do community mapping.

“When people started doing recovery things here there was a lot of talk about speaking at conferences and training staff. And I knew I couldn’t do that. But someone encouraged me and my friend to find out if we could put up a few posters, just in our area. Now a lady who runs a shop asks us if we’ve got any more posters for her, as her customers notice them. It shows that even shy people can do a good job to promote recovery.”

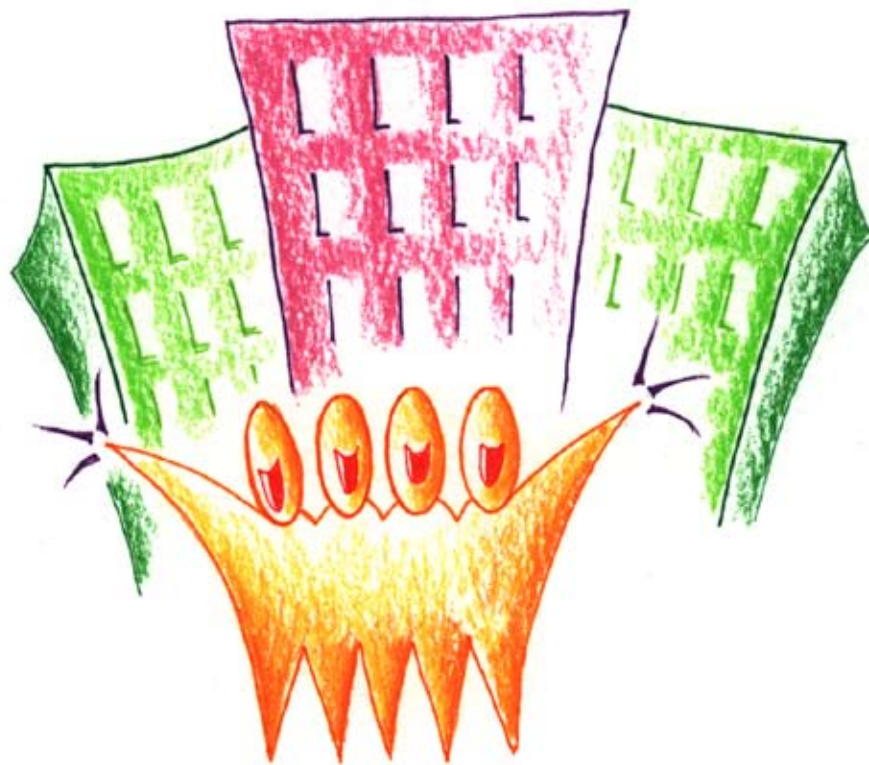
People in the local networks have found that these are also good ways of reaching people who have experience of mental ill-health but don’t have any contacts with mental health services or projects, so have not heard anything about recovery.

Example

A man read about a recovery conference in the local newspaper. The article encouraged everyone with an interest to come along, so he did. For many years he had been receiving treatment for his mental health problems from his GP. He did not have contact with any other people with similar experiences.

This was the first time he had a chance to hear how other people were coping with their health and having a good life. They were also talking about their hopes and dreams, and the plans they were making.

He has stayed in touch with people and groups he met at the conference. He has told them that hearing about recovery has changed the way he thinks of himself, and that has changed his life.



Learn how to
INVOLVE OTHERS
in the community...

Essentials for whatever you do

- Encourage people to take part.
- Everybody needs time to reflect.
- Recovery sometimes isn't easy for people and people need support.
- Remember that there is a person at the centre and they dictate the pace.
- Remember to check that people feel included.
- Celebrate diversity.
- It's ok to take time out, go at people's pace.
- Recovery isn't a straight line. Developing a recovery network will have its ups and downs and loops too.
- Look back to see where you have come from and how far you're travelling.
- Enjoy your achievements and each other's company.

Contacts for more information



Scottish Recovery Network
Baltic Chambers
Suite 320 – 321
50 Wellington Street
Glasgow G2 6HJ

T: 0141 240 7790
F: 0141 221 7947
E: info@scottishrecovery.net
www.scottishrecovery.net



Anne Connor or Margaret Timoney
Outside the Box Development Support
6 Harmony Row
Glasgow
G51 3BA

E: anne@otbds.org
E: margaret@otbds.org
T: 0141 445 3062
www.otbds.org