

Making

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Starting from people's lived experience

Outside the Box is working with the Scottish Recovery Network to support the development of local recovery networks. This is one of a series of resource leaflets developed to support local recovery networks in Scotland. The material in these leaflets comes from the emerging experience of the people in the pilot areas, feedback from people in other places, and what we know about the development of any network which is supporting change.

The companion leaflet is ***Putting a network together***. There will be further leaflets in the series over the course of 2006.

Some of the examples and quotes in this leaflet came from a session which Outside the Box organised for local recovery networks in June 2006. Material from this workshop will be on the website.

Recovery starts with people's lived experience

The root of the recovery movement across the world is the lived experience of people who have had mental health problems. They found out what enabled them to live well. A recovery approach recognises that people who have had mental health problems are experts by experience.

Some people in the United States of America who first started defining the way people used their own experiences to work out what kept them well as recovery. They shared these ideas with other people in other places.

“What matters most is not whether we’re using services or not using services; using medication or not using medications. What matters in terms of recovery orientation is, are we having the life we want to be living? Are we achieving our personal goals? Do we have friends? Do we have connections with the community? Are we contributing or giving back in some way?”

Patricia Deegan, one of the leading people promoting recovery in the United States

In Scotland, we have been talking about recovery for some years. In November 2002, there was a workshop in Dundee, at which people talked about their experiences of recovery. One of the outcomes from this was the Scottish Recovery Network.

“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.”

Introduction to ‘Would Recovery Work in Scotland?’, report of the 2002 workshop

The Scottish Recovery Network website has links with activities promoting recovery in other countries. The report on the workshop in 2002 is on the website, along with other background resources and reports. The website also has the personal accounts of many people in Scotland who have described their recovery journey as part of the Narrative Research project.

See www.scottishrecovery.net

These are ways your local recovery network can remind people about the roots of recovery in people’s lived experience.

- Make links with activities to promote recovery in other places – for example, following up some of the contacts in the SRN website and at SRN conferences.
- Invite people in your area to describe what keeps them well and what living well means.
- Read the personal accounts on the website, and talk about what they mean to you with a couple of friends or colleagues.
- Find out about approaches to support individual people’s well-being and recovery that are based on people’s lived experience.
- Look at the ways in which mental health services in your area plan and assess their outcomes. Do they reflect people’s experiences of what makes a difference?

“We are going to get in touch with the Patients’ Council, so people who have been in touch with hospital services for a long time can be part of the network. Recovery isn’t just for people who are diagnosed today. It’s for everyone.”

Making sure people are at the centre of the network

“You show what recovery means in everything the network does.”

The activities of a local recovery network themselves have to reflect the values of recovery and support recovery for individual people. These are some of the ways this will be apparent.

- People who use services are part of planning and developing the direction of the network - what it does, how it works, what the values are.
- The way the recovery network is organised and what it does supports people in their recovery.
- There are lots of ways for people to contribute, which reflect people's strengths and preferences.
- For each person who gets involved in a local recovery network, this can be in the way and at the time that is right for them.
- There will be opportunities for people to get involved when they want to. Getting involved is easy and welcoming.

- People can choose not to be involved in the network, or can be involved and drop out when this suits them.
- The recovery network respects and builds on what people who have mental health problems have been saying for some time.

These are ways your local recovery network can help people be at the centre:

- Ask people what recovery means to them. Do this at the pace and in the style that suits them.
- Check out with lots of people who use services what they would like a recovery network to do.
- Have lots of ways for people to contribute – both to the activities of the network and in planning and organising what the network does – so everyone can find the ways that suit their skills and gifts.

There are more ideas in the leaflet ***Putting a network together.***

People being at the centre of the care and support they use

“Recovery is about each person’s own journey. It isn’t something that can be done to someone, or become a type of service.”

“Recovery is harder when you have no choice and no say in any aspect of your life.”

Having a say in what happens to you

Many people describe how services that listened to them and gave them the support they needed played an important part in their recovery. They also describe how their recovery involved using ordinary, mainstream services instead of relying solely on specialist mental health services.

People who use mental health services and staff who work in services in parts of Scotland where recovery networks are getting underway have described how using person-centred planning or person-centred approaches to planning and delivering care

has had a big impact. These approaches help people think about what will support recovery for each person, and then take actions that help this to happen.

“We’ve been focussing on managing symptoms. Now we’re focussing on what each person needs in every aspect of their life. At first I thought that would make things more complicated for our team, but it’s making them much easier. It’s making a big difference for our clients and for us.”

Getting access to support to have your say

These are ways in which people have their say and stay in control.

- Using independent advocacy projects.
- Getting support from other people through collective advocacy groups.
- Having friends or family who stand with you and give you help and encouragement to make choices.

- Using the opportunities in the 2003 Mental Health (Care and Treatment) (Scotland) Act, such as advance statements, which set out what someone wants to happen when they are unwell, and identifying a 'named person' to support them and protect their interests.

These are some ways in which your local recovery network can support people having their say.

- Hold workshops around person-centred planning.
- Hold workshops around the provisions of the new Act and how these might be helpful in people's recovery.
- Gather accounts of how people have been helped to be in control of what happens to them and how this helped their recovery.
- Make links with local advocacy projects – individual advocacy and collective or group advocacy.

“You can't take charge unless you have self-awareness. But that is difficult if you have been embedded in the system. The real you is lost and it is necessary for you to rediscover the real you. What are my likes and dislikes? What am I frightened of? What do I enjoy doing? What are my dreams? This takes courage and strength and support, but it can be the first steps.”

People telling their personal stories

“Telling a true story about personal experience is not just a matter of being oneself, or even of finding oneself. It is also a matter of choosing oneself.”

(Harriet Goldhor Lerner)

Telling your story or personal account is a way for people to get their own recovery experiences across to other people. Because it is based on a person’s own recovery experiences, telling an individual story has a powerful message of hope for other people thinking about their own recovery. Stories can also enable those people who are supporting people on the journey – families, friends, staff who work in services – to understand what this experience was like and what they can do to help.

Some people find it easy to tell their story. Other people find it very difficult. But there are ways which will help make it easier and give more people the choice on whether they want to tell other people about their journey.

Get advice and get lots of practice.

- Get advice from people who have done this before – both people who found it easy and people who took time to get comfortable at it.
- Go to a storytelling workshop if there is one in your area.
- Find people who can support you to when you want to tell your story. Practice telling it until you find the points that you particularly want to get across and are comfortable with what you are saying.
- After you’ve told your story you may want to talk to someone about the experience. It’s all part of your story!
- Find out about what storytelling means in different cultures.
- Get together with some friends and listen to each other’s stories.

Think about different ways for you to get your message across.

- Writing your story is just as effective as speaking it out loud. It can then be read out by another person.
- Look out for writing workshops in your area. They can help you explore your story in a safe manner and help you feel more confident.
- Use poetry or creative writing, if these are forms you find helpful.
- Use creative arts – photographs, drawings, sculpture.

Once people do feel confident about telling their stories, there are many ways you can use these personal accounts to share the message around recovery. Most people will prefer to take on one or two ways of sharing their story, but not others – or at least at the beginning. So working out what is right for you is also part of the process.

- People can tell their experiences to other people who have mental health problems.
- People who have lived through their own recovery can talk to families.

- People who are relatives or friends of people who have had a serious mental health problem can talk to other families about recovery – their relative's and their own.
- People can talk to staff who work in mental health services – for example, as part of a training programme.
- You can talk to staff who work in mainstream services and help them understand what they can do to help people in their recovery and understand how important they and their services can be.
- You can talk to community groups and raise awareness about recovery, or link this to other aspects of raising awareness, such as tackling stigma.
- People can speak at bigger conferences.
- Staff can reflect on their experiences of recovery – what helped them to understand the experiences of their clients or patients.

These are some ways your local recovery network can support people to tell their story.

- Organise a storytelling workshop, if there are none in your area.
- Make opportunities for people to get together and share stories in confidence.
- Make a DVD of people telling their stories.
- Put together a collection of people's stories and get copies or get it printed.
- Put on an art exhibition around what recovery means to people.
- Look at the material produced by SRN and by local groups across Scotland. Discuss how you could introduce these to people in your area.
- Support each other to tell your recovery stories through the press or radio.

“My recovery journey only began when I told my story.”

These are some points to remember when people are making their stories public.

- Think about whether you prefer to use your own name, or an alias, or be anonymous.
- Watch that you don't reveal more about yourself than you mean to.
- If anyone else is named, check beforehand that they are ok with this.
- Think about the level of detail you give – the point you want to make might come over better if there is less detail.
- It often helps when a couple of people read over it and give suggestions on how to present the story to best effect.
- Make sure you have someone to talk to about how it feels to make your story public.

There are useful guidelines about making your story public on the SRN website, at Narratives and Research.

“We really like the stories on the Scottish Recovery Network website, so we've decided to gather our own local collection. But we are going to include the recovery stories of carers and of people who work in mental health services too.”

Links with ordinary community resources

“Recovery is what individuals do. Facilitating recovery is what workers in services do. Supporting recovery is what a community does.”

People have described how they have drawn on a huge range of people, activities and resources as part of their recovery. A useful source of information is the SRN narrative research project, which can be read on the website and in the reports and extracts that are being published.

Local recovery networks can help build good links between people who have mental health problems, people who work in mental health services, and people who are part of ordinary community activities and resources.

Community mapping

One useful tool is community mapping, which helps to build knowledge of the area. A local recovery network will be different in each area and should reflect the services and organisations that are already operating.

There are 2 main reasons why community mapping helps you ground a network in people’s lived experience.

The first is that this is another way for people to tell their own story. When people take part in mapping out the ways in which this community can support recovery, they can talk about what helped them: the book they found in the library where someone described their experiences, the art class at the community centre, the ethnic minority women’s group where someone asked them to be a helper as well as a member, and so on.

The second reason is that it can help your network to show other people the link between what people found was helpful in their recovery journeys (realising they were not alone, discovering new skills and interests, making a contribution), the people and resources in your community you want to reach out to, and what can help other people in their recovery journeys.

There are several ways to do community mapping.

One is to make a list of all the groups in your area.

Another is to get a very big piece of paper (joining long strips of lining paper works well - you get it in wallpaper shops) and make a rough map of the area, with the main roads, river, local landmarks etc. Then people draw on it or put up stickies for the groups they belong to or know of. You can make this as bright and creative as you want – colours and symbols for different types of groups,

someone making drawings of people and buildings for other people to just stick up..... At some point, someone will probably have to turn this into a more conventional list, but you can go back to the big map too.

Whatever approach you use, there are some points to remember.

- The starting point is people's lived experience. It is the community that has meaning for them.
- Your map will help you plan which people and organisations you can work with as allies now, and who you want to reach out to and persuade to do things differently.
- You decide what geographic area you are going to cover – your town, your local authority area, the NHS Board area, your local neighbourhood. You can use the same approach for any one of them (as long as you find a big enough piece of paper).
- Your map includes all the resources that can help people on their recovery journeys. So it includes all the ordinary community services as well as mental health ones. It also includes informal groups (neighbours, the blokes at the pub) as well as more formal groups and services.

- Include communities of interest – women's groups, faith communities, and so on.
- Include the statutory organisations that people use or need, like the Benefits Agency and Housing Associations.
- You can include the people and places that *could* be part of recovery, but are not yet working that way in your area for some people.
- Don't try to do it all in one go. People will remember more groups later, or want to change things.
- Include a mix of people to put together the initial list or drawing, and then check it out with other people. Include people from a wide range of places and situations – ordinary community networks as well as mental health ones.
- The process of discussing what to include and how to describe it is important too. A good guiding rule is that if one person thinks it is relevant to recovery for them, then it is in.
- Enjoy doing the mapping. Include fun, food and friends as part of what you do.
- Come back to your map from time to time. Add to it and make changes – are there more groups you've come across and want to add?

These are some of the ways your local network can build strong links between mental health services and ordinary community resources.

- Invite people who work in community services or are members of community groups to local events about recovery.
- Hold events in ordinary places rather than only in mental health settings.
- Get posters and leaflet about recovery into places such as libraries, post offices, leisure centres.
- Offer some sessions for staff and volunteers in community services around what recovery is and what they can do to help.

“Our first task is to find out what is happening in our area.”

“Everyone can be involved in Recovery. It helps to build relationships with other organisations and communities.”

Links with user and carer participation

Recovery is not the same as user and carer participation, but there are close links between them.

Recovery is about each person finding what recovery means for them, and finding their own path to it.

User participation is the range of ways in which people influence what happens to them, and in what services are developed in a local area. Every person has the right to be involved in their own care. Every person also has the right to give their views on what services would be useful in that area.

- For many people, becoming active in user-led groups has been a significant step towards recovery for them. The friends they make and the roles they learn to take on mark a move away from being a patient to being someone who makes a contribution. These people and skills can sustain someone through the good times and the more difficult times.
- There may be times when a person does not want to think about recovery. But he still has the right to participate.

- Someone may not want to have much to do with mental health services and how they are planned. Recovery may be a big part of her life, with people and activities around her which have nothing to do with mental health services.
- Some people will want to use their experience about what aids recovery and feed in these ideas through community planning and other ways of influencing the opportunities and services for everyone.

These are ways in which your recovery network can build good links with user participation in your area.

- Make sure that user and carer participation networks receive information about recovery – from your network and the SRN material.
- Link in to any participation network in your area of people who use a particular service or who have strong links with a particular service provider.
- Check if you can hold some sessions to raise awareness about recovery at places where the user and carer networks meet. Consider organising these as joint sessions between the 2 networks.

- Ask for ideas about what the recovery network should be doing from members of the user and carer participation groups.
- Link back regularly to the people at the user and carer networks who are on committees or formal planning groups, so they know what is coming up through the recovery network activities.

“Remember that people need time to find or regain enough confidence to take part.”

“Getting involved in user groups has been part of my recovery. That gave me the strength and support to move on to other things.”

Links with independent advocacy

These are some of the ways independent advocacy projects are working alongside people as part of their recovery journey.

- Many people have found that support from an advocacy project over a difficult period or issue helped them become more confident and better able to advocate for themselves.
- Advocacy projects are supporting people to get care and support that meets their individual needs and help their recovery.
- Collective advocacy groups have been identifying the wide range of supports and services that help people as part of their recovery, to the benefit of people living in that local area.
- For some people, Citizen Advocacy provides an invaluable form of longer-term support and links with the community.

More information about independent advocacy is available from the Scottish Independent Advocacy Alliance:
www.siaa.org.uk

Listening to carers' experiences

The experience of friends and families of people who have mental health problems around recovery has been mixed.

- Some people have been a significant part of the person's recovery journey.
- Many carers have heard little about recovery.
- Some people need to recover from their own experiences, for example, when contact with services was difficult, or when the symptoms of the person's illness put a strain on relationships.
- Many people describe the stigma around mental health and the ways they became isolated from friends and neighbours. Some carers are now rebuilding their own social networks.
- Some people got good peer support from other families and want to share this now.

- Some relatives and friends want to be part of changing public awareness and attitudes around mental health and show that recovery is possible, especially when communities are welcoming.

These are some of the ways your network can help make carers welcome.

- Make contact with carers' groups.
- Give carers an opportunity to tell their stories.
- Ask carers what recovery means to them.

"I still have nightmares about the night I had to agree to my daughter going into hospital. But I was so frightened by what she was doing to herself, that she could die. I want to recover from that."

"All those years, I kept saying that I couldn't move on with my life because my son was ill. That's what we were told it would be like for the rest of our lives. Now I've realised, he has his life and it's ok. It's not the same as my other son's but that doesn't matter. He has friends and interests that he cares about. He is getting the support he wants from all sorts of places. He's living with his illness. He has moved on and has found a good life. Now I need to do that too."

"Can carers and families be part of a recovery network?"

"Can I help? I can tell other families that there is hope."

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.

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