Challenging ideas in mental health

Reflecting on recovery

Liz Barclay
Professor Peter Beresford is from Brunel University. He is also the Chair of "Shaping our Lives", a national user controlled organisation. He has been a user of Mental Health Services and is an academic and a prominent figure in the mental health world h Dr. John Hopton is from the University of Manchester. He has trained as a nurse before becoming an academic, specialising in mental health issues. And Dr. Jan Wallcraft works for the Sainsbury Centre for Mental Health and the National Institute for Mental Health in England and has been a user of Mental Health Services, is an academic and very active in the survivor movement. Jan Wallcraft, if I can come to you first. What exactly is "Recovery"?

Jan Wallcraft
The way I've looked at it is that it seems obvious that if somebody can have a breakdown, a mental illness, they should also have the possibility of recovering. But it seems that in most mental health literature that possibility of recovery never appears. We are trying to say that this should be a key factor in any kind of mental health service: that the possibility of recovery should be looked at and the means of helping somebody recover should be the most important aspect of mental health work. Recovery is not the same as cure or being completely well or being "normal" in inverted commas; it is self-defined. Each person has a concept of where they want to be when they come through their mental distress or mental illness and that is the concept that should be worked with. What does that person want to achieve? What are their hopes for their own future?

Liz Barclay
So when you say the mention of recovery doesn't appear in mental health literature, are you saying that it's not a widely held belief that recovery is important?

Jan Wallcraft
I think it has not been a widely held belief that recovery was even possible. Once somebody had a diagnosis of a severe mental illness they were seen as that was it for life. They were never really going to be a full member of society again. But actually if you look at most of the research where people have been followed up over years, the proportion of people who recover is quite high. Even with a serious illness such as schizophrenia, maybe a third of people actually recover their lives completely, a third of people will make social recovery, which is they can get back to living a fairly good life even with some disability. Maybe only a third of people won't really recover but probably even those figures could be improved if recovery was addressed in the way that I think it should be addressed.

Liz Barclay
Dr. Hopton is that your experience too – that recovery is perhaps not accepted as a main stream concept?

John Hopton
It was certainly true when I was training as a nurse in the seventies. I mean there was a very popular sort of way of explaining things like schizophrenia to patients and to the relatives of patients as encouraging people to think of schizophrenia as being something analogous to diabetes where as a diabetic has to take insulin for the rest of their lives so the person diagnosed with schizophrenia would have been encouraged to believe that they would need to stay on medication for the rest of their lives. In which case there certainly wasn't an idea of recovery around and I think that that kind of idea is still around. I am not sure that it is as prevalent as it once was but certainly it would not be uncommon amongst mental health

professionals of my generation, people who trained in the sort of ‘sixties, ‘seventies, possibly even in the late ‘eighties, to have that view.

Liz Barclay
Who defines recovery?

John Hopton
There is a history of mental heath professionals latching on to labels and imposing their own interpretation on them. So I think it is important that if this concept of recovery is going to be a progressive one, it is important that recovery is defined by the person who is experiencing distress and not by any sort of self-proclaimed expert I think really.

Liz Barclay
Professor Beresford, pick up that point about labels. Are labels always a good thing or are they something that are latched on to in a way which are counter-productive?

Peter Beresford
Well I think this label’s a very interesting one because it's both quite a recent development and something that's very old. I think it's interesting for example if we re-visit the nineteenth century we can find the establishment of organisations like the Mental After Care Association, which is still in operation, which very much took the view that people could get better and set up after care services for people leaving what were then the old asylums. But what worries me of course is who’s introduced the idea this time round and who will be defining it and because we know of the inequalities of power that there are in the mental health system, the very limited power to define of mental health service users and the considerable power of some professionals, I have serious concerns. And I also think that it’s been quite a divisive idea so far because some mental health service users are finding it quite helpful and I think that Jan gave a really positive definition as mental health service users would like to see it develop. But of course that is not necessarily the way that the idea is going to develop and the idea has been imported from the States and has really been advanced very much from the top down.

Jan Wallcraft
The notion did originate in the United States but it was developed there initially by service users. It was then taken up by the University of Boston, and developed as a concept. And I agree with Peter that there is the danger that this concept like many other concepts such as normalisation could be taken over by professionals and I think it's really important that we just keep on saying that that is not the way that it should develop and I would not support that.

Peter Beresford
I think that there is a more fundamental problem really and I think you have highlighted the ambiguities that concern me. You only can recover if you are ill. If you are ill then maybe you can get better. I think for many of us in the mental health service users/survivors movement part of the really big problem is the reliance that there still strongly is on a medical model of mental illness underpinning policy, provision and practice. And it's a medical model that unfortunately, and I am sure the intention isn't necessarily there, pathologies us, focuses on the individual incapacities, deficiencies, problems, things people can't do. Where I think what’s at the heart of what you are saying is really about developing, building on what people can do. And I think so long as we’re dependent on a medical model that is going to be very difficult.

Liz Barclay
John?

John Hopton
I do agree with you. I think there is this sort of difficulty that if you talk about recovery it does tend to imply an illness model. And then I thought well how can we get round that? And I thought about something like the way in which an athlete might use the term “recovery” in the sense that if you go on a long run, you need to recover from it. But the run hasn’t made you

ill, but if you don't have a proper planned and well thought out recovery you certainly may suffer some kind of ill effect for want of a better word from it.

Liz Barclay
Would getting that message across to mental health professionals require a large shift of thinking?

John Hopton
I think if you can get them early enough you can sometimes do it but I think the difficulty with that is again it comes to the problem of the nature of organisations and the nature of institutions. Again, when I was training as a psychiatric nurse in the 1970s it was an era when there was a lot of change in the wind. There were quite a lot of new ideas around and all we ever got told as student nurses when you sort of complained about things that were happening on the wards was "it's up to you to change it" but as a student nurse you were the least powerful person in the organisation. So it probably took about twenty years for that generation of people to get into a position of leadership within the profession before any real sort of substantive change came along.

Liz Barclay
There must be other changes required in order that people will have the support and back up they need in order to recover.

Jan Wallcraft
You don't have to have a concept of illness in order to recover. You can recover from a broken heart; you can recover from a broken leg. We can recover from almost any life situation and people who have had a crisis in their life; they do need a period of recovery whether or not they identify that as an illness. And I think it's important that people are given that space to find their feet again and find what they want to do with their lives. There are a lot of things that would enable recovery to happen better and I think some of those are very practical things such as the benefit system. I think one of the reasons that service users are particularly concerned about this idea of recovery is the fear that somebody else, some mental health worker or doctor will define them as recovered and then take away their services and their benefits. And I think it is genuinely going to be difficult to promote the idea of recovery if we can't address the issue of benefits and people's rights to get back into a proper job.

Liz Barclay
And Professor Beresford, getting back into a proper job must be another ….

Peter Beresford
Well it is and it's very closely related to this whole discussion. It does concern me because I think we are hearing very much from the progressive wing of discussion about recovery here. And of course I think people are right that we can bend these words to constructive purposes. But what worries me is that this is an idea which hasn't in this country at least, and the movement of mental health service users in the UK, is different to the movement of mental health service users in the United States. It hasn't come from mental health service users and we are trying to make the most of it. But we have other ideas, which have come from us, which I think can be far more helpful, ideas which might have good relationships with recovery and might actually offer alternatives to recovery. I think ideas like "self-management" are very, very helpful here. How we can learn better to deal with those issues that affect us. But also I think that some mental health service users, an increasing number, are beginning to learn from the ways in which the disabled people's movement in the UK and internationally has done it's thinking and developed a social understanding of issues of disability which are transferable with change and development to mental health service users which focus very much on issues of rights and overcoming barriers. And what worries me most about the medicalised mental health system we have here is that it under-explores, it under-plays issues of barriers and the barriers are what most concern us now. There are really big barriers, which we need to challenge, like stigma, stereotyping, unemployment, discrimination, isolation and the rest. And I don't see how a medically based, because that's the dominant model of recovery, is going to help us take that forward successfully.

John Hopton
One of my concerns about the concept of recovery is that certainly the psychiatric profession and large sections of the various sort of mental health professions still accept the validity of a diagnosis such as personality disorder. And there is still a debate around amongst mental health professionals as to whether or not personality disorder as defined by psychiatry is treatable. And I think one of the difficulties that we have with the concept of recovery; it opens the door to blaming the person who gets the diagnosis of personality disorder for their problem; blaming them for not getting better. And I think that is one of the major anxieties I have about the concept.

Liz Barclay
Do you mean that puts pressure on people who don't recover? Or puts pressure on people to make attempts to recover that possibly make the situation worse?

John Hopton
It's a bit of both I think really. I mean, several writers in the past have made the observation that the label "personality disorder" is a very convenient diagnosis for a psychiatrist to put on a person who he doesn't know how to help because once you put the diagnosis "personality disorder" on to a person, then you've legitimised the fact that you can't help that person because it's in the literature that people with a personality disorder may be untreatable, or are untreatable if you read some books. And I think it's that issue, it's that idea of blaming the person about sort of absolving yourself of a responsibility as a helping professional for helping someone because this person will not recover. Therefore, "It is not my fault; it's their fault".

Liz Barclay
But what about the people who have been much damaged and are very seriously mentally ill – will they recover? Can they recover?

Peter Beresford
Perhaps we should think about a different way of expressing that concern which is that with appropriate support, with challenges being made at a broader level to barriers, what can those people contribute? In what ways can they regain and maximise their potential? And bearing in mind that we know people who are actively involved in contributing in all sorts of ways as far as is possible who have been labelled as having severe and enduring mental illness, who have had the most terrible times, who have had many times in hospital over long periods and still can contribute. I think we really need to dissuade ourselves of the use of prophecy here, that what we can say is that people who have had the most difficult experiences over a very long time can still do things. But I would like to go back to that point that Jan raised about benefits and contribution because benefits are such a big barrier to contributing. We were asked by the Ministry in Shaping our Lives to do some work, to produce a report from talking to service users around the country about how well they were able to do what Government wants them to do, to participate, to get involved in policy and provision and over and over again we have been hearing from people that they are inappropriately frightened of losing their benefits, that they live in fear that, if they take part in something, that might happen. It will take ages to sort them out. Local offices, who with the best will in the world, don't actually know how to do it.

Liz Barclay
And presumably if they were to have another illness would then find that their benefits didn't kick in quickly enough?

Peter Beresford
Absolutely right. Or another episode of difficulty. Yes.

Liz Barclay
It is your experience that if people can contribute at some level, that will be a catalyst to recovery?

Jan Wallcraft
I do think that is the case. I think the important thing about recovery is it's linked to hope, the concept of hope. I mean people have tried to define what hope is. It's a hard thing to define but many people who have talked about recovery, their own personal recovery, have said that it was triggered by regaining hope, regaining self-esteem, regaining self-confidence. And I think those are really important issues for mental health workers to consider. How can they contribute to somebody regaining hope? They can't make that happen. It's not a thing that they can force but they should be contributing to a person regaining some hope and self-esteem and sense of purpose in life. I think the importance of using a target such as recovery, using a word such as recovery, for mental heath workers is that that can be or could be a way of measuring and evaluating what they do. How far does that contribute to a person's recovery again as defined by the person themselves? And if mental health services is not contributing to recovery, and if social services are not contributing to recovery, then why not? That might be a way of looking at the things which block recovery such as the benefit system. The social exclusion unit have been told by many, many service users that they cannot be properly included until the benefits issue is resolved and the benefits trap that they are in.

Peter Beresford
You used one of the words which I think is most important here – developing self-confidence. And I was an advisor to a user-controlled research project; people who had not done research before, who hadn't been in work for ages, and during the course of that project one of the women got a job and she wrote us all a letter saying she didn't think that she would've had the confidence to take that step back into a job without the kind of gaining of skills, the working with other people, that she had got from being on the research project. And I think that's what we are actually talking about here. In fact I feel that I am hearing this discussion as kind of like the word 'recovery' getting in the way of a whole mind set of developing good ideas, building confidence and so on and so forth. And also this idea that you have to be ill before you can get better, I think that we should start looking a bit more at the way that direct payments are beginning in this society to work for some mental health service users. And I listened to one who has been accessing them for a while and she said it's not all hunky dory. She still has very real difficulties but she's convinced that having the support and with direct payments you control the support that you have, you get the kind of support you want and it tends to be non-medicalised support because that's what people want, that she felt several times she has avoided having to go in to hospital. She has avoided periods of quote: "illness" to recover from.

Liz Barclay
But picking up on that point about the word "recovery" getting in the way. Are there people for whom it simply does get in the way Dr Hopton?

John Hopton
I find the term "recovery" works fine for me. If I am talking about depression, if I am talking about post-traumatic stress disorder; if I am talking about anxiety; if I am talking about the absolute terror of a severe psychotic experience, it makes complete sense. But the difficulty that I have with it is over the last ten or fifteen years we've seen new ideas developing in relation to self-harm. We've seen new ideas developing in relation to voice hearing which has sort of encouraged us to think of this as part of the way of being in the world for many people, something that we don't need to recover from. There has been some research done apparently which has shown that self-harm is now higher in Britain than anywhere else and problem listing this because it is sort of affecting people who are even younger. And I thought, "hmm - where does this leave us?" You know, we have taken hundred years of psychiatry to get to a progressive view of self-harm and now this discourse is moving backwards again and I could see the use of the term of "recovery" perhaps getting in the way of that.

Liz Barclay
So where does all of this leave us? What are the practical implications of this concept if it is rolled out and it does become a much more important part of mental health services?

Jan Wallcraft
I see it as a changing paradigm or a changing model. If we talk about mental health services in terms of a recovery model then they would have to change the way that they work and the way that they operate and the way that they link up with other branches of service, such as Social Services and perhaps, you know, lessen the barriers between ideas of illness and distress and probably stop using some of the negative labels that they use and maybe just look at problems and distress and how to help people through those. It doesn't have to be called recovery but looking at ideas of helping people to have a positive life again then recovery can be a hope inducing word for some people. For other people self-management of their problems is what works best for them. But services need to be working towards helping people live a positive life style and 'recovery' is one way of changing the paradigm.

Liz Barclay
Professor Beresford?

Peter Beresford
Well I don't want to devalue the really positive ideas that underpin commitment to this idea of recovery but I think sadly that public policy, policy developments, tend to degrade and institutionalise very good ideas. I thought normalisation was a good example that you offered Jan. And I worry about their becoming another tyranny because one of the things that I have noticed very much with mental health service users is that people don't want to replace one tyranny with another. People want a much more free approach which is based on people being able to generate their own ways of dealing with things, their own ways of managing their lives, the kind of service that might work for them rather than some sort of orthodoxy. And I worry that this is going to impose both on service users and on service workers another externally imported orthodoxy.

Liz Barclay
Dr. Hopton - there is a balance to be struck here?

John Hopton
I can see the positive aspects of it and I can see the negative aspects of it. I spoke before about the view that was prevalent in the seventies about the idea of telling people who had a diagnosis of schizophrenia that they needed to be on medication for the rest of their life – now I can see how a concept of 'recovery' could be used to actually change people's outlook on that kind of thing in the sense that you could actually suggest to somebody that you might use medication to recover from that period of those sort of distressing thoughts, the hallucinations or the thought disorder or whatever it was and then once you were through the crisis that you could then, having recovered from the crisis with the use of drugs, that you could then go on about sort of finding new ways of developing confidence.

Peter Beresford
I still can't see how we will benefit from using a term with power imbalances, which is always going to take us back, however much we are reluctant to do that and however much more exciting and different ways of thinking we can bring in to, you know, "If there is a problem, if the person is ill then here is an ally, an allied idea – 'recovery'". And I think we should really be looking to some of those self- generated ideas which are becoming really powerful, which are not becoming unhelpfully controversial, getting in our way as people and becoming a barrier between us, but which mean that people may really have those chances. I sometimes find it very difficult to take on just how bad mental health services routinely are. We are starting from a terrible base.

Jan Wallcraft
I think the idea of recovery is challenging both to service users and to mental health workers. I think if people feel that they can't recover in their lives then maybe they need a challenge like recovery to say well actually maybe you can do better, maybe you can start to dream again about the things that you used to dream about not just about managing your problems but actually you know living the life you have always dreamed of. I think that can be a helpful challenge to service users, certainly service workers, mental health workers and psychiatrists need the challenge of "If you are not helping your patient recover why not and what could you

do that might help them recover?” I like the challenge of it. I think it's controversial but I think that can be a good thing.

Liz Barclay
Dr. Jan Wallcraft, Dr. John Hopton and Professor Peter Beresford, thank you.