The recovery group: A service user and professional perspective

Sarah Morgan¹ and Jerome Carson²

Abstract: In this paper we describe the contemporary importance of the recovery approach in mental health services. Recovery is one of the main service drivers. Thus far, much of the focus has been on individuals and their unique recovery journeys. Groupwork, may have a key role to play in the continued development of the recovery approach. We present the Recovery Group, an innovative approach to involving service users in recovery. A 'colour piece' illustrates a single groupwork session. If clinicians and policy makers are to truly place service users centre stage in the recovery process, more innovative methods of engagement are needed.

Key words: recovery; service users; groupwork; positive psychology; engagement

Freelance journalist and service user, Streatham, London, England
Consultant clinical psychologist

Address for correspondence: Dr Jerome Carson, Consultant Clinical Psychologist, South West Sector CMHT, 380 Streatham High Road, Streatham, London, England. SW16 6HP. Jerome.Carson@slam.nhs.uk

Introduction

Recovery is the current *zeitgeist* in mental health services worldwide (Piat, *et al.*, 2008; Shepherd, *et al.*, 2008). Almost uniquely in the mental health field, it is an approach that has been embraced by policy makers, mental health professionals and service users. Perhaps most significantly, it places the service user centre stage. As the Social Perspectives Network paper rhetorically asks, 'Whose Recovery is it *Anyway*?' (Social Perspectives Network, 2007). It is of course the service user's recovery. Yet paradoxically in an era dominated by evidence based medicine and randomised controlled trials (but see Marzillier, 2004, for an alternative perspective), it is an approach that has largely arisen from the developing service user literature (Roberts & Wolfson, 2004), sometimes also referred to as First Person Accounts (Hornstein, 2006). In this paper we utilise two narratives. The Introduction and Discussion are described by the second author, a clinical psychologist and the 'Colour piece' narrated by a service user, the first author.

From a personal perspective, the excitement of the recovery approach is that it is a concept that is only beginning to be articulated. While some might argue, rather like the earlier social role valorisation or normalisation approach, that it is an ideology in search of a technology, this is also part of the challenge. A first attempt has been made to link the recovery approach and Positive Psychology (Resnick & Rosenheck, 2006). In an attempt to bolster the underlying theoretical structure of recovery, other researchers have attempted to bring in selfdetermination theory as an underlying mechanism for understanding recovery (Mancini, 2008). Whatever approach one takes, it is impossible to ignore the dynamic service user literature. Three workers are mentioned here, though there are numerous others who could be cited. The three workers I report on are Patricia Deegan from America, Retta Andresen from Australia and Julie Leibrich from New Zealand.

One of the most influential advocates of the recovery approach is the American clinical psychologist and activist, Dr Patricia Deegan. I first heard Patricia speak at the World Psychosocial Rehabilitation Congress in Rotterdam, Holland in 1996. She talked about recovery as a journey of the heart. 'The goal is to become the unique, awesome, never to be repeated human being that we are called to be, (Deegan, 1996, p. 92). In this sense our collective therapeutic task, becomes one of helping

Sarah Morgan and Jerome Carson

individual sufferers move towards a process of self-actualisation, rather as Maslow had suggested many years earlier. Clinically, I have used Patricia's work to teach hundreds of mental health professionals to learn more about recovery. (I purchased her conference presentation, but her work can also be bought from the National Empowerment Centre in the United States and via Patricia's own website. In the new world of the Internet, she can be found on YouTube). With individual service users, I show them the video, while I make notes highlighting the specific material in the video that applies to their own unique circumstances. Consequently, and somewhat sadly, Patricia Deegan now assures me I hold the world record for watching that particular video (Deegan, personal communication)! I recently showed the video to a service user with psychosis, who also has a daughter with psychosis. The video has a resonance for both of them.

The second approach that deserves especial mention, is that of Retta Andresen and her colleagues in Australia. The starting point for their work on recovery was to survey the existing service user literature and to use this to devise a theoretical understanding of the process (Andresen et al., 2003). Their definition of recovery is, 'The establishment of a fulfilling meaningful life and a positive sense of identity founded on hopefulness and self-determination,' (Andresen et al., 2003, p. 588). They argue that there are four key psychological processes involved in recovery. These are hope, self-identity, meaning in life and responsibility. They suggest that there are five stages to the recovery journey; moratorium, awareness, preparation, rebuilding and growth. They have developed a validated tool to determine which stage an individual is at, called the Stages of Recovery Instrument (STORI), (Andresen et al., 2006). There is also a single item scale called the SISR (Self-Identified Stage of Recovery). I have found this second scale very helpful in working with individual service users, due to its obvious brevity and its face validity. While the initial standardisation of the STORI showed a range of scores across the five stages, in our own local services in Inner City London, the bulk of our service users are at the lower end of this scale. Nonetheless, the work of Andresen and her colleagues is important and has also inspired other researchers, such as the developers of the Mental Health Recovery Star (McKeith and Burns, 2008a; McKeith and Burns, 2008b).

The third approach to mention briefly, is that of Julie Leibrich in

New Zealand. As part of a project established by the Mental Health Commission, Julie set out to gather a set of narrative accounts of the recovery process, as a way of tackling the stigma attached to mental illness. What evolved over a two year period, was probably the best ever collection of service user accounts yet published, entitled simply A Gift of Stories (Leibrich, 1999). The book contains 21 accounts of living with the complete range of mental health problems from clinical anxiety to psychosis and from individuals spanning the width of the social spectrum. The book is lavishly illustrated and designed. While there are other similar books (Barker, et al., 1999), these are not as consumer friendly to read and indeed 'savour.' Leibrich argues that the process of recovery is as much a process of discovery and that the process can be growth enhancing. Tragically one of the contributors took his own life before the book was published. As Peter Chadwick reminds us, 'madness can kill' (Chadwick, 1995). This needs to temper our enthusiasm, whilst not detracting from our core task to provide hope. How do we take this work on recovery and bring it into our groupwork with service users?

The recovery group

Like many service innovations, the Recovery Group emerged by serendipity. Our Community Mental Health Team (CMHT) had been running a monthly user group for a number of years. I volunteered to help with this. To try and revitalise this group, I arranged for a number of speakers, for example, a colleague ran an interactive session on music therapy. One particular meeting was attended by a single service user, a nurse and myself. There was clearly a need for a radical change. At the end of a self-esteem workshop, I happened to inform the participants about our forthcoming World Mental Health Day event. One service user asked if she could exhibit her artwork and photography, and if she might also help out with organising on the day. Colleagues working in this area will appreciate this is an unusual occurrence. Having seen the quality of this woman's artwork, I asked if she might be willing to put on a small exhibition of her work and give a talk at the CMHT. Her presentation 'Seeing through psychosis,' was attended by over 20 people and showed her artistic journey from

fashion design to art photography. It took her several weeks to prepare for this exhibition. The talk was also attended by a number of staff. I co-facilitated the second Recovery Group (Carson and McNary, 2007), which suggested that service users themselves held the 'keys to recovery.' In this session, Michelle talked about a film she was going to be making about the recovery process. This was commissioned by the South London and Maudsley Trustees, and is nearing completion. (A booklet of the stories of the four service users featured in this film, as well as two more academic accounts on recovery, has recently been published, Carson et al 2008). The third presentation in the series, comprised me interviewing another service user in front of the group, about his own emerging understanding, and of the recovery model we had jointly developed (McManus and Carson, 2008). The fourth in the series was from Dolly Sen, one of our service users who had written two books of her own life and history of mental illness (Sen, 2006a; Sen, 2000b). The fifth presentation is described in detail by Sarah below. The sixth was from a 65 year old service user who talked about 'Lessons from the University of Life.' She recounted the story of her life in three main sections, illustrating each with family photographs, music and poetry, as well as her own narrative. Other sessions are in the planning process, but the best way to give a 'feel' for the Recovery Group is to let Sarah tell the story in her own words.

'Colour Piece' on the Recovery Group.

A blue door on Streatham High Road near the station. No sign. Just a door and an intercom complete with camera. Thankfully it's at the end of a small passage that gives shelter from the glaring sun, while you wait, for quite a long time, for someone to buzz you in. After being buzzed in there is an ascent that is hardly welcoming and a little bit clinical.

The reception could be any doctor's surgery apart from the fact that the receptionist is behind a pane of glass. I tell them that I am here for today's Recovery Group organised by Jerome Carson, the head psychologist. There are a couple of people waiting. It doesn't seem that many of them are that ill because they don't seem that distressed, but schizophrenics have their high points even in the depths of their illness and depressives often hide it well.

Jerome walks in, jug in hand, and beckons meenthusiastically into the restricted area complete with key pad. It's cooler here than the reception area, though neither has windows so the reason for this is somewhat inexplicable.

Along a corridor lined with room after room with nothing but chairs and sometimes a table, we reach the largest. Thankfully it has windows and is cooler still. It is also decked with appliqué art pieces on the tables and the wall. I am left to survey one of the large appliqué wall hangings with a woman on a green and white background reaching to the sky, she seems to be dancing.

As I'm looking I am introduced to Ibo, who is speaking at today's recovery group. It is her art that is arranged round the room. All of her artwork is striking and quite varied, but I compliment her specifically on the piece with the woman reaching to the sky.

She stands talking to Jerome who is busying himself with organising drinks and nibbles. People start to filter in one at a time, soon the room is half full and starting to feel like a social club. Some people clearly know each other well and chat idly as they wait. Finally a tall black man comes in pushing a buggy. This is Ibo's son, he has come to film his mother talking and retreats to the back with his camera.

Jerome opens up the presentation saying: 'Well familiar faces and a couple of new ones.' He has a very jolly manner, as he goes on to describe Ibo's son as 'a very handsome chap', he's the kind of man you wouldn't hesitate to ask to be Father Christmas for a primary school fayre.

He mentions me and 'Michelle at the front here in the wrap around shades'. She smiles as she is mentioned. As well as being part of the recovery group she is recruiting for a film she is doing.

After prompting from Jerome, Ibo starts to chronicle her life from when she started art college. She is very matter of fact and has the air of a school teacher as she relays her story. The mood in the room has quickly changed from that of a social club to something more akin to a lecture hall.

Ibo gets more animated as she stresses that had she not

been so ashamed of her families' financial difficulties her tutor could have found her some kind of assistance. Her desire to be part of the black movement in America led her to move to an all girls black college. It was there that her 'ethnicity came through.' This ethnicity is evident in a lot of the work that she has displayed around the room, particularly the greeting cards that she has displayed, which have monochrome stylised African women's heads.

She talks of leaving that college and selling her work in Africa, which helped with the second lot of her family's financial difficulties. Despite the nature of what she speaks about she rarely shows emotion. So her enthusiasm when she talks about her work taking off is marked: 'You know it was selling, it was actually selling.'

Then she moved back to her mother's home country, where her work didn't sell. Jerome prompts: 'Very interestingly around that time you actually destroyed some of your work.'

She laughs slightly as she says: 'I did.' Then laughs again as she begins to describe how her work came to a stand still. She was producing but not selling and after several months she became so frustrated that she simply: 'Tore everything up and threw everything in the bin.' Again she speaks with an unusual degree of detachment.

She started building a portfolio again, trying to re-create some of her work from memory, but several months later she destroyed this as well, again due to the same frustration. Emphatically she says people commented on and loved her work, but they weren't buying it. She decided at that point that she would find something else to do rather than destroy her work: 'Go out, visit a friend, visit relatives, do something' she puts a lot of emphasis on this last word.

Then she went back to university in London to do a bachelor of education degree with art as the major subject. A degree that she enjoyed but found 'the work was very heavy,' she pauses between each word as if talking about this at all is an effort.

Then: 'Two years into my stay,' there is a sigh in her voice, 'I got my first psychotic episode, so I couldn't actually continue.'

Over the next three years: 'I actually stumbled along,' she pauses, 'in life without having contact with services.'

Finally her mother was quite worried about her and decided she needed some help. She is eager to stress that she did. So, as an outpatient, her psychiatrist sent her off to a work project for people with mental health problems.

At the printing department there, one of the members of staff saw her drawings. She asked if Ibo would illustrate an African cookery book she was writing. Ibo did and was given a copy of the book, which sits alongside the appliqué work at the back of the room. She is clearly proud of this work, but she is far from brash.

Jerome says jovially 'So you started there as a sort of member, ... and they saw the quality of your work and then you became poacher kind of game keeper.' Ibo laughs at this. 'They asked you to become a member of staff.'

Two years after getting her first job with them, they wanted a crafts manager. In this role she made artefacts for sale and had between six and ten people working under her that either suffered from mental health problems or had learning difficulties. She enjoyed the work: 'but it was quite frustrating at times', because people would get confused about what they were meant to do and do something different, her voice is heavy with disappointment.

But she rallies: 'But we muddled through, we muddled through. ... Even though there were people suffering with mental health problems and learning difficulties they were quite talented. ... Some of them were very artistic.' One year a greeting card they designed, was fought over by about two or three organisations.

Then she moved into appliqué. About five years ago she was in a slump and not doing any art work.

She says: 'I am a Christian, before I became ill ... even though I was going to church I wasn't living a proper Christian life, as I should have been... But after I became ill, I re-directed my life to the Lord.' So she prayed for inspiration and was inspired to do appliqué. This story animates her much more. 'I wasn't taught how to do appliqué. I simply, for some

reason I just knew what to do,' she laughs slightly.

Naturally spirituality is very important to her work. 'I feel that spirituality in my work is a wonderful way of honouring him (God). ... The Lord helps me to stay well.'

Jerome asks her why African imagery in her work is important.

'I'm from West Africa, I love my African heritage, I love being black, I just revel in the fact that I'm from Africa.' She gushes. 'And I think African art is unique, I think African art is bold, I think African art is exciting, I think African art is vibrant.'

She says in the future she would love to have an African art business where she can sell hers and other African art, or have her work sold in famous well known department stores. She wonders whether that is possible, but says passionately that she wants to: 'be a world class artist and have my work well known world wide.'

As Jerome opens up questions from the audience, everyone applauds.

A woman sitting on my left with a very meek, slightly hesitant manner, says: 'I'm a Quaker and so spirituality interests me a lot. ... I don't think quite so intensely and thoroughly as you.' She smiles. 'I turn to that side of my life, always really,' she continues earnestly, 'that what Quakers call`that of God' is the most absolute beauty you can find,' as she talks she stops herself as she becomes confused in what she is saying, before finally saying she doesn't feel you need to do Godly images to honour God.

Ibo responds by saying: 'I have no other way of expressing myself. ... but if I put my work in a shop and it's got a spiritual image it might cause them to think and to question.' She says earnestly.

'That's why I wear my crucifix.' She holds out her large cross with a Jesus on it as she says this: 'I don't believe this protects me really,' but she thinks that this, like her artwork, may make the people she meets think about God.

One woman in the audience wants to know if she has been influenced by her psychosis.

'No. I haven't not at all in fact,' she continues: 'when I have a

relapse I can't work.' She asserts: 'I don't have the motivation, I don't have the desire, I don't have the inclination.'

An old middle aged man sitting on his own right to the side of the room begins talking. Much of what he says is hard to make out as he is quiet and his speech is somewhat confused: 'You've done a lot of good things. I did work in a restaurant, which is for people with mental health problems. And I think most people in this room would like to go to this restaurant. It's run by a good team. And I like to think that it got me back to being a service user...' He isn't asking a question and eventually trails off.

Michelle asks if Ibo was ever hospitalised and for how long. She asks her questions in an almost business like manner. Ibo has been in hospital twice, first for four weeks, then for five.

Michelle continues with her grilling, moving on to asking about medication. Ibo responds that she takes medication: 'Every day.' in a dutiful manner and laughs.

Michelle wants to know if Ibo shares her experience of finding she feels different and finds everyday tasks hard to do when she misses doses.

'No. If I miss some, because ... sometimes I do forget and sometimes I deliberately don't take it. If I feel like I've had enough I don't want any more, but that was in the past, I don't do that now. ... I'm a lot more sensible and more wise now. Yes but one or two days is not a problem,' She adds speculatively: 'but a week, hm.'

Michelle wants to know if that means she gets depressed. Ibo says no she finds her: 'symptoms start to creep in little by little.' Further questions from Michelle reveals that she starts to hear voices and may see things.

Michelle underlines this very matter of factly: 'Right, hallucinations.'

Ibo says: 'Paranoia, that's the first thing to set in... Then I know. Oh oh do something quick.' She laughs.

Again the man sitting on his own goes off on a bit of a undirected ramble. Jerome has to cut him off slightly saying: 'Emma you have a question.'

Emma's question reveals that Ibo isn't working, just doing

art at home. After a follow- up question from Michelle, Ibo says: 'Last year March it just got too much for me and I couldn't cope.' Ibo stresses that she is fine now though and fit to work.

The Quaker woman asks how she manages: 'to make space in your mind ... to sit down and concentrate on your work?'

'I don't seem to have a problem with that for some reason. I don't know. Because when I'm well, I'm very well,'

'You're in control.' The Quaker woman supplies in an understanding tone.

'I'm in control. ... And you know I want to do it and I'm motivated to do it and I enjoy what I'm doing. So it just flows.'

'If you do have distractions you can let them flow over you.' 'Yes, yes, yes.' She says deliberately. 'And I don't have too many distractions. Yes. I guess it's a gift.' She muses. 'Because I can sit down in a week and just reel off my work. ... Without feeling tired or anything I think it just comes I think it's a gift.' She says distinctly. 'It's a gift.' She adds softly.

The woman next to Michelle says she has felt she was a Christian, even though she wasn't brought up as one, as it transpires lbo was. With the transient nature of her own beliefs, the woman wants to know if lbo has ever had doubts.

'Um, I've never had doubts.' Ibo says very deliberately and certainly. 'And I found that even when I became ill I hung onto the Lord for dear life.'

She continues: 'I've been blessed not to have doubts. That again is a gift. ... even in the thick of the illness I've never doubted I've actually hung onto the Lord for life. For dear life', she says emphatically 'just to keep me going through the tunnel'. She feels there's: 'nowhere else to go.'

Jerome closes the session saying: 'The more revealing questions have come from the audience,' everyone laughs 'not from the psychologist actually. Now we've all learnt something today... Ibo thank you ever so much, thank you for putting all your work into the portfolio and please don't rip the portfolio up, because there's some beautiful work there... Please thank Ibo for being brave today.' Everyone applauds and the mood returns to that of an informal social club. Ibo's

story may have been told in a matter of fact way, but her story and the earnestness of the questioning has cast a spell. Now that has been broken.

(apart from Jerome Carson and Michelle all names have been changed).

Discussion

The Recovery Group is an unusual form of groupwork. Attendance is open to any service user, or member of CMHT staff. Group sessions touch on a number of key groupwork principles, such as universality (Yalom, 2005). Indeed as the above 'colour piece' suggests, the group had a greater desire to discover whether Ibo was a fellow sufferer, by asking her about her admissions and medication, than the facilitator had planned in his carefully pre-structured interview. Yet, the Recovery Group has reinvigorated our previous user group. Few service users are however natural presenters, and considerable work has to be put in beforehand, to help devise a method of presentation that each service user feels comfortable with. With Margaret, we worked on her session for several months. Likewise Gordon and myself spent several weeks co-developing a model of his personal recovery. I am currently working with another service user, who feels he will not even be able to read out his presentation, so we will have to have someone do this for him.

There are a number of benefits to the Recovery Group. For each service user that presents in front of the group, this is a major achievement. They are able to share their talents, knowledge and wisdom with fellow sufferers. A secondary benefit is that staff get to discover how talented many of our service users actually are. Interestingly within our own Trust, staff were provided with 4½ days recovery training, yet no training has yet been provided for service users. This is also the case elsewhere, (Crowe, *et al.*, 2006).

The Recovery Group is only one way of bringing in a positive, hope filled supportive network for individuals with long term mental health problems. Other workers have used mindfulness groups (Chadwick, *et al.*, 2005) and hearing voices groups (Coupland, *et al.*, 2002). We are also working on a number of different groupwork initiatives. This year

I co-facilitated a joint workshop with Dolly Sen. Our service users are increasingly involved in our annual World Mental Health Day event. Last year one service user sang two opera arias. This was the first time she had sung in public for 15 years. I am currently developing a recovery workshop programme for service users, that will run over a 10 week period, partly based on the work by Andresen, Deegan and Leibrich, described in the Introduction. This will be co-facilitated with a service user.

Patricia Deegan suggests that staff need to see service users as heroes, who have survived (Deegan, 1996). In a small way, a number of our local initiatives are trying to do this. On day 1 of the staff recovery training, staff were introduced to four recovery heroes. These were Mary Ellen Copeland and Patricia Deegan from America and Peter Chadwick and Rachel Perkins from Britain. Now we have our own local heroes. It is not just our service that has local heroes. Every service has them.

References

- Andresen, R., Oades, L., and Caputi, P. (2003) The experience of recovery from schizophrenia: towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37, 586-594
- Andresen, R., Caputi, P., and Oades, L. (2006) Stages of Recovery Instrument: development of a measure of recovery from severe mental illness. *Australian and New Zealand Journal of Psychiatry*, 40, 972-980
- Barker, P., Campbell, P., and Davidson, B. (Eds.) (1999) From the Ashes of *Experience: Reflections on madness, survival and growth.* London : Whurr
- Carson, J. and McNary, M. (2007) *Recovery from Mental Illness: Do service users hold the keys to our understanding*? Unpublished paper. (available on request from Dr Carson)
- Carson, J., Holloway, F., Wolfson, P., and McNary, M. (Eds.) (2008) *Recovery Journeys: Stories of coping with mental health problems*. London : South London and Maudsley NHS Foundation Trust (available on request from Dr Carson)
- Chadwick, P. (1995) Understanding Paranoia: What causes it, how it feels and what to do about it? London: Thorsons

Chadwick, P., Newman Taylor, K., and Abba, N. (2005) Mindfulness groups for people with psychosis. *Behavioural and Cognitive Psychotherapy*, 33, 351-359Coupland, K., Macdougall, V. and Davis, E. (2002) Group work for psychosis. Mental Health Nursing, 22, 6, 6-9

- Crowe, T., Deane, F., Oades, L., Caputi, P., and Morland, K. (2006) Effectiveness of a collaborative recovery training program in Australia in promoting positive views about recovery. *Psychiatric Services*, 57, 10, 1497-1500
- Deegan, P. (1996) Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal*, 19, 3, 91-97
- Deegan, P. Patricia's work can be accessed via the web on (http://www. patdeegan.com/)
- Hornstein, G. (2006) Bibliography of First Person Narratives of Madness in English. (3rd ed.) Available via the Internet or via the second author as a .pdf file
- Leibrich, J. (1999) A Gift of Stories. Dunedin: University of Otago Press
- McKeith, J. and Burns, S. (2008a) *Mental Health Recovery Star: User guide.* London: Mental Health Providers Forum
- McKeith, J. and Burns, S. (2008b) *Mental Health Recovery Star: Organisational guide.* London: Mental Health Providers Forum
- Mancini, A. (2008) Self-determination theory: A framework for the recovery paradigm. *Advances in Psychiatric Treatment*, 14, 358-365
- Marzillier, J. (2004) The myth of evidence based psychotherapy. *The Psychologist*, 17, 7, 392-395
- McManus, G. and Carson, J. (in press) *From Communism to Schizophrenia and Beyond: One Man's Long March to Recovery.* London: Whiting and Birch
- Piat, M., Sabetti, J., and Bloom, D. (in press) The transformation of mental health services to a recovery oriented system of care: Canadian decision maker perspectives. *The International Journal of Social Psychiatry*
- Resnick, S. and Rosenheck, R. (2006) Recovery and positive psychology: Parallel themes and potential synergies. *Psychiatric Services*, 57, 120-122
- Roberts, G. and Wolfson, P. (2004) The rediscovery of recovery: Open to all? Advances in Psychiatric Treatment, 10, 37-49
- Sen, D. (2006a) *The World is Full of Laughter*. Brentwood : Chipmunka Publishing Sen, D. (2006b) *Am I Still Laughing*? Brentwood : Chipmunka Publishing
- Shepherd, G. Boardman, G., and Slade, M. (2008) *Making Recovery a Reality*. London: Sainsbury Centre for Mental Health
- Social Perspectives Network (2007) Whose Recovery is it Anyway? Social Perspectives Network, Paper 11. London: SPN (Downloadable from www. spn.org.uk)
- Yalom, I. D. with Leszcz, M. (2005) *The Theory and Practice of Group Psychotherapy*. (5th ed.) New York: Basic Books