Valuing peer support

A review of literature on peer support in helping people with mental health issues towards personal recovery. Alex Williams May 2011

Abstract
This article reviews a broad range of written material about peer support for people with mental health difficulties. Its aim is to share examples of peer support in practice through showing the effectiveness of this approach for those taking an active part and its correlation with Recovery practice as adopted by mental health service providers. The intention is to make resources on peer support accessible to a wide audience, so that individuals affected by mental distress and their supporters, KMPT working together with voluntary sector providers, can learn from existing evidence. This shared learning holds the possibility of organisations more fully utilising peer support as a resource within local contexts. The benefits of peer support are fully demonstrated through the written material. A way forward is suggested in people with lived experience of distress and use of services being paid as peer support workers and group facilitators. This step of paying for peer support for those who want this arrangement values their contribution, provides chosen employment and changes the nature of the mental health workforce to one that challenges discrimination and is truly recovery focused. The review shows that the creation of the right conditions for peer support could empower individuals with lived experience of mental distress to lead and change services as well as taking control of their own lives.

Introduction

Aims and methods
Research is featured on the value of peer supportive relationships in treatment programmes, self-help groups, online communities and self-management initiatives. This is followed by the use of peer support as an alternative to hospital admission for those in mental health crisis. Instances and evaluations of paid peer specialists in mental health services in both Scotland and England are outlined. The review does not debate the appropriation of Recovery by mental health services but instead focuses on raising peer support higher up the mental health care agenda to have maximum effect.
This review looks at various types of literature: published research papers, project summaries and articles including published material and grey literature. The author has chosen this diversity of material to reflect pioneering work done in the voluntary sector which may not yet have been formally evaluated. The literature has an international scope, but with particular focus on implementation in NHS services and the voluntary sector in the UK. The literature search was carried out through the internet search engine Google, websites about recovery, Google Scholar, professional journals, books and personal contacts. Exclusions were papers before 1995 and peer support unrelated to mental health.

**Definitions**

This paper gives separate definitions for recovery and for peer support. While the definitions are accepted ones, alternative explanations and emphases within both subjects exist in other literature sources.

**Recovery**

The following definition is used across a range of literature on recovery, (1)

*A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. Recovery is often a complex, time-consuming process. People with mental illness may have to recover from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from lack of recent opportunities for self-determination; from the negative side effects of unemployment; and from crushed dreams...Recovery is what people with disabilities do. Treatment, case management, and rehabilitation are what helpers do to facilitate recovery.*

(Anthony, 1993)

**Peer support**

The foundation for peer support is spontaneous and naturally occurring support among people with mental health problems. A theoretical approach has been developed by Shery Mead, an independent trainer and survivor from New Hampshire:

‘Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another’s situation empathically through the shared experience of emotional and psychological pain.’ (2)
Evidence for health improvement
There is an evidence base that peer support can have a positive effect on participants’ mental health. Published in 1999, a significant review of the evidence for peer support among individuals with severe mental illness takes a historical overview of identified peer support in treatment programmes including democratic therapeutic communities and 12 step abstinence groups such as Alcoholics Anonymous. Pat Deegan is quoted in this paper as she made a plea for role models who were also surviving schizophrenia. Deegan herself served as such a role model for others living with a highly stigmatised diagnosis when she became a national leader in the mental health consumer/survivor movement in the United States. The same literature review finds that mutual support groups improve symptoms, promote larger networks and quality of life. Research into the effectiveness of formalised peer support was still at an embryonic stage at that time, but the authors conclude ‘This review of the feasibility and usefulness of peer support among individuals with serious mental illness suggests that people with serious mental illness may constitute a promising but little utilized resource in the recovery of their peers’. (3)

Recently published research analysing 10 randomised control trials of peer support interventions for depression has shown measurable therapeutic benefits including decreased isolation, provision of role models and reduced stress (4) A previous large multi site RCT of telephone based peer support carried out in Canada found that participating women’s risk of developing postnatal depression at 12 weeks postpartum was half of those in the control group. Each woman had eight contacts from their peer volunteer and 80% were satisfied with their peer support experience and would recommend it to a friend. (5)

Mutual self help
The central importance of relationships in supporting recovery is highlighted by Mike Slade. He states that there are three different types of peer support the first taking place in a supportive group context:

‘Mutual self help groups give primacy to lived experience, leading to structures based on the assumption that all participants have something to contribute.’ (6)

The contributory and reciprocal nature of self help groups is recorded by Self Help Nottingham. Personal narratives expressed through written letters share valued themes of
having friends, finding hope, building social relationships, the relief of speaking freely and sharing in a group, the importance of normality, acceptance, a safe space, and realisation that ‘you are not alone’: (7)

‘Deep connections are made when members identify with the experiences, emotions and reactions of fellow members. Participants benefit from helping each other and by pooling coping strategies, sharing information and drawing on the collective wisdom of the group..... This powerful mix of acceptance and mutual support provides an environment in which there are no fixed ‘roles’ – the helped becomes the helper and the desire to reciprocate is valued and celebrated’

Peer support will have a different feel and level of organisation depending on its setting. The mental health charity Together commissioned two survivor researchers to consult with members of five groups. (8) Two of the groups (CAPITAL and Borough Wide User Forum Rochdale) saw peer support as part of each group’s function, with support remaining spontaneous and informal. Reading Resource and members of Rochdale WRAP viewed peer support as a more formal relationship between two people where one is offering support to the other on the basis of shared experience, with systems of training, support and supervision for peer workers. The Peer2Peer group’s opinions were a mix of both perspectives. Some members from several of the groups felt that there was a risk of service users being offered the opportunity to become a peer support worker ‘before they were ready’ or on an ‘ad hoc’ basis without training or support. There was a perceived risk of professionalising peer support compromising its essence, though boundaries and standards could also lead to a more effective service. People across the five groups agreed that peer support had a positive influence on the mental health of everyone involved:

‘The benefits of peer support are clear, with shared identity, increased self confidence, developing and sharing skills, improved mental health and wellbeing, accompanied by less use of mental health and other services emerging strongly from the discussion groups. There is an increased role in information sharing and signposting for those involved in peer support. People felt that peer support challenged stigma and discrimination. For those involved in giving one to one and more formal peer support there was also the benefit gained from helping others.’
There is a diverse range of mutual support groups based on self identification with certain diagnoses or distress symptoms, for instance those groups affiliated to MDF (Bipolar Disorder Organisation), and the Hearing Voices network. Meeting locally, participants share similar experiences and strategies for living. There is usually no charge for attendance, meetings have no hierarchy and are planned on a regular basis at the same location. Voluntary sector projects are trusted by members to host these meetings which often rely on the individual efforts of volunteers as group leaders.

Online forums may also have an important place in someone’s support circle, one example is Borderline UK on Yahoo groups and message boards requiring registration on websites by charities including b-eat, Anxiety UK, OCD UK and National Self Harm Network. An instance of online peer support adapted by an NHS Trust is provided by Cumbria Partnership NHS Trust, Department of Psychotherapy and Itinerant Therapeutic Community. The website www.itc4u.org has restricted access; it can only be used by service user members and staff of the therapeutic community. This ‘service user led network of out of hours care’ has shown positive results in promoting members’ personal safety outside the times the community meets, ‘admissions to psychiatric hospital fell by 50%, contact with the police fell by 70%, days our service users spent as inpatients in psychiatric hospital fell by 90%.’ (9)

Group work may be psycho-education and training aimed to improve condition management. ‘Insight Training’ targeted at bipolar disorder has been evaluated as an effective intervention which improves mood stability, symptom severity, coping, quality of life and greater empowerment. The programme was devised by Heather Straughan, an expert by experience and research associate. The training ran over 12 weekly sessions each lasting three hours, comprising lifestyle advice and personal skills training encompassing a holistic approach to dealing with this complex mental illness. The participant feedback identified the user led nature of the training working alongside its self help elements. ‘These two aspects combined with and strengthened participants’ knowledge base of the illness. Overall these fed into improvements in mood recognition and improved management, with much improved capacity to deal successfully with their mood swings.’ (10)
**Intentional Peer Support**

Shery Mead’s model of ‘Intentional Peer Support’ has been recognised and used by many mental health support services. Its intentional element exists to: ‘purposely communicate in ways that help both people step outside their current story’ (11), IPS is linked with WRAP (wellness recovery action planning). WRAP was originally developed by Mary Ellen Copeland as a resource enabling people with mental health challenges to learn about, monitor and maintain themselves in recovery through identifying triggers, planning actions and ahead of crisis times. (12) Intentional peer support often involves the use of WRAP among peers. Mead delivered her five day IPS training to a group of 30 participants in Devon during 2007. Praise offered by Glenn Roberts, consultant psychiatrist in rehabilitation and recovery with Devon Partnership Trust captures the IPS philosophy:

‘Intentional peer support is peer support with an intention –that of moving towards what you value and want in life as steps towards your own recovery. People naturally support each other when someone is going through emotional distress. Intentional peer support capitalises on this natural phenomenon, and tries to augment it and make it more productive and helpful.’ (13)

The evaluation of this episode of training (14) studied the proportion of participants who remained involved with general peer support and IPS after the course. At five months 15 of the 26 in the study were still involved in peer support with one member setting up an IPS based group (Chard Intentional Support Group). Opportunities to practise and receive support affected the amount to which trainees could continue with IPS, ‘without identified work roles or organisational support for the development of peer support groups, it is very difficult to use or sustain it in isolation.’

**Crisis alternatives**

Personal acute mental health crisis presents a time of vulnerability, risk and change. Crisis points may lead to the involvement of the person’s GP, NHS crisis resolution and home treatment teams, the police, Mental Health Act procedures and acute psychiatric wards. Responsive 24 hour crisis services, including out of hours cover, are a priority need for service users, carers and commissioners (Kent and Medway Live it Well strategy 15). Acute
care is expensive and may be coercive at times. However, two case examples show that peer led alternatives can be effective, preferred by service users, less expensive and proven successful in preventing hospital admission.

The Leeds Survivor Led Crisis was established in December 1999 as one of the UK’s first ever survivor led crisis centres. This award winning centre opens Fridays-Saturdays 6 pm – 2 am when most other services are closed, employing six permanent part time support workers and eight bank support staff who all have personal experiences of mental distress including self harm. The Centre operates a telephone helpline, provides a physical place of sanctuary for those in acute crisis and offers group work. The service’s main role is hospital admission prevention which has significant savings ‘Cost per day for one acute hospital inpatient is £259, at the centre it is estimated to be £178’. (16) Core funding comes from Leeds Adult Social Care, NHS Leeds and the Leeds Personality Disorder Clinical Network. Project manager Fiona Venner describes their model as ‘person centred and non medical and non diagnostic.’ Up to 75% of callers are suicidal and up to 51% of visits have a connection with self harm, many have been the victims of abuse and experience exclusion from mental health services due to ‘challenging’ behaviour and a diagnosis of ‘personality disorder.’ Self harm is permitted within parameters at Dial House and recognised as a way of managing psychological pain. The team’s approach to crisis is that it can be ‘a liberating or learning experience, that people should have a range of choices for dealing with a crisis and that each person must feel safe, listened to and connected to other people.’ (17) Demand for this service means that many people have to be turned away with visitors prioritised in terms of their desperation and level of isolation. Visitors’ comments bear testimony to the centre’s support given to manage their own risk while in crisis.

‘Coping with the same difficulties as last year, I’m not around people in hospital who are self harming and destructive. At Dial House people are trying to cope in positive ways.’ (18)

Peer support to facilitate early hospital discharge has been established and evaluated in Southern Adelaide, Australia. (19) For the period of 14 June to 31 August, $113,066 was saved as a direct result of the project which is quantified in currency of $93,156 (after allowing for modest set up and delivery costs). There was overwhelming satisfaction by consumers with the way in which the service was delivered.
The peer support workers supported people in the community to avoid hospital admission or to leave hospital early. Packages lasted 8-12 hours in total over a 1-2 week period. This input, acted as ‘community bridging’ for those with little social support at risk of leaving hospital with a week’s medication and not seeing their GP during the wait for referral to community mental health services.

‘Their presence gave consumers evidence and hope for recovery. Consumers reported a distinct shift in their view of themselves and people with mental illness with many consumers actively setting goals and achieving them. Only a small proportion of consumers relapsed to hospital either during or after the support period. Of these, more than half did so in the context of physical health conditions.’

**Paid peer specialists**

People with lived experience of mental distress can be integrated in the mental health workforce providing benefits for employers, service users and peer workers. Precedents exist especially in the US where there a numerous and diverse range of consumer run services (20). Efforts made internationally to achieve the recruitment of peer support workers in mental health services have often been stimulated by government funding and policies. Since 2005 a programme of development of peer support worker roles has been supported by the Scottish Recovery Network and the Scottish Executive as a means of promoting recovery. The national peer support worker pilot scheme has been evaluated showing successful implementation and many benefits to service users, peer support workers and the wider system. One important finding was that peer support workers operate best when based in settings already committed to recovery principles – those in the peer support worker role cannot be expected to act as the sole agents of change. Service users welcomed the peer support worker role which also reduced the ‘us and them’ nature of relationships between service users and staff. (21)

A number of NHS mental health trusts in England are currently utilising and remunerating peer support. These pilot projects take a partnership approach between local user led voluntary sector projects and the NHS service provider. There is no single training curriculum to equip potential peer support workers to carry out this role since the content of
courses varies according to the model of peer support. Sutton Mental Health Foundation has trained and employed peer support workers providing a service for inpatients at Springfield Hospital, part of South West London and St George’s NHS Mental Health Trust. Research on the IPS scheme on Jasper Ward (22) examined peer workers’ experiences and the extent to which peer support contributes towards recovery based practice within the NHS. The peer worker role was reported as a positive experience including contributing towards personal recovery for these workers and perceived benefits of working as part of a supportive group. Though there were initial challenges around working relationships with ward staff these were overcome during the study period. Safety was an issue of concern given the volatile nature of acute wards with the need for further training indicated here.

Nottinghamshire Healthcare Trust is a Trust leading in national community practice in peer support. The Trust funded peer support workers to visit acute wards at Highbury Hospital and Queen’s Medical two afternoons a week from April 2010. Trust Recovery lead Julie Repper described the potential of peers to inspire and model recovery for those in crisis ‘These people embody hope and will really show people they can do it. Lots of people don’t believe recovery feels possible. This gives the peer support workers the chance to get into paid work and to use their problems to help others.’ One of the peer support workers, Kevin Beard, explained their role to mirror recovery ‘People can be scared – we want to provide the light.’ (23)

The Health Foundation has since awarded a grant of £398,000 to Nottinghamshire Health Care Trust, extending the project for three years. Potential workers receive training from Nottingham voluntary sector organisation Making Waves working with the Institute of Mental Health through an accredited ten week course (based on a model from Arizona 24) includes topics such as listening skills, ethics, boundaries and team working. Repper comments that the effect of seven new peer workers is likely to be ‘powerful change, for individual service users and their carers it will increase self belief, hope and empowerment, improve their social networks help them develop coping strategies, and will hopefully reduce their use of mental health services. ‘(25)

Six NHS mental health services trusts have been selected by the Centre for Mental Health as Supporting Recovery demonstration sites on the basis of outstanding progress in integrating recovery into their services. Three of the Trusts leading in recovery practice have shown
commitment to the employment of service users and peer support workers. Cambridgeshire and Peterborough NHS Foundation Trust and Dorset Healthcare University Foundation (working with Dorset Community Health Services and Dorset Mental Health Forum) both perform strongly in this area. (26)

**Conclusion**

The quantity of information available together with project examples and wide enthusiasm for peer support provides evidence that the implementation of peer support is helpful and potentially transformative of existing mental health services. The benefits of peer support are clearly illustrated in the featured material. However, when planning for increased take up of peer support initiatives, consideration needs to be given to the wellbeing of the peer support workers.

Mary O Hagan has written about service user integration in the mental health workforce in New Zealand in a way that now feels relevant to an English context: ‘philosophically it is the ethical thing to do. On a pragmatic level it is the sensible thing to do. On a policy level it is the expected thing to do.’ She described service users as an ‘untapped resource’. (26)

Parallels between this international example and England exist with strong ethical and practical grounds for valuing and rewarding peer support. Questions need to be asked about how much we expect service users and survivors to do for free when they provide a highly effective and expert support system.

The impetus for change in recognition and payment of peer support is multi dimensional. On a practical level those with mental health problems have a high unemployment rate. A significant section of this group may also find their benefit status changes due to far reaching reforms to the welfare benefits system. These government reforms are designed to reduce benefit dependency and ‘worklessness.’ Since 2008 new claimants for sickness route benefits have claimed Employment and Support Allowance with its stated priority of helping disabled people back into work. Over the next 3 years existing claimants of incapacity benefits will be ‘migrated’ to ESA involving being retested for their fitness to work under a much tougher work capability assessment. This medical assessment is part of the decision making process dividing claimants into three groups: (1) people who are seen as able to work immediately transferring to jobseekers allowance, (2) those who need intensive support to return to work
while on the work related component of ESA or (3) claimants who are incapable of doing any work at all who will continue to get full unconditional benefits. Statistics from the pilot migration to ESA (which took place in Burnley and Aberdeen from October 2010) show the majority of claimants are placed in the first two categories, making their benefit contingent on getting back into work of at least 16 hours a week. (27)

One problem that is likely to emerge is that although it could be claimed that peer support as a voluntary activity prepares service users for future employment, a deficiency in career progression hampers these efforts and lets this group down. Volunteering for an indefinite period is not an option unless the volunteer is among the minority of those placed into the support group of ESA. As these changes take effect, there is a risk that the talents of service users are lost since many will be required to actively seek and take up any available paid job.

While some service users may wish to do peer support on an unpaid basis since they feel that the voluntary nature best fits the ethos of their self help group, commissioners and providers should not assume that all people with mental health issues will be able to take this position.

Peer support workers do not replace existing services and staff but instead work alongside them, enhancing understanding of user perspectives and recovery focus. Peer support in groups, for instance using WRAP, are not a replacement for group therapy either – though peers are able to co-facilitate groups with psychologists and allied professionals. Peer support should not be seized on by funders as the basis for a cheaper service. It is an effective service mainly when financially supported and mainstreamed into mental health provision. Jobs as peer workers need to be of adequate hours and sustainably funded. Where mental health trusts expect service users to carry out consultancy or lead recovery group work on an erratic self employed basis, this often complicates any receipt of ongoing benefits and changes their personal tax status rather than providing ideal opportunities.

There are challenges around where peer support ‘sits’ within mental health services which can be orientated in the medical model while holding compulsory treatment powers. Uneven access to statutory services can also derive from a focus on diagnosis rather than assessment of individual need. Peer support may be part of improving the service user experience within a service context but still needs support at the highest level of mental health trusts to succeed.
In conclusion, peer support deserves to be championed across the mental health service and community. Peers, including peer support workers, possess the potential to inspire others going through mental distress, enabling them to achieve self defined goals, meaningful relationships and new hope of recovery.

   http://www.centreformentalhealth.org.uk/pdfs/Making_recovery_a_reality_policy_paper.pdf
   Recovery www.mentalhealthshop.org/.../100_ways_to_support.html
   Voices of Experience, Narrative of Mental Health Survivors,’ Edited by Basset T, Stickley T, 142-150 Wiley-Blackwell
12 Copeland, M E http://copelandcenter.com/what-is-wrap/
http://www.recoverydevon.co.uk/download/Ley_JPMH-9.1-March.pdf
16 James A (2010 ‘A beacon of help’ Mental Health Today February 18-19
17 Leeds Survivor Led Crisis Centre ‘What we believe’ project published information, obtained from the project manager
20 http://www.power2u.org/
24 http://www.recoveryinnovations.org/riaz/peer_training.html
25 Nottinghamshire Health Care Trust website http://www.nottinghamshirehealthcare.nhs.uk/aboutus/latest-news/funding-boost-for-peer-support-worker-project/
26 Centre for Mental Health, Recovery demonstration sites
   http://www.centreformentalhealth.org.uk/across_mh/supporting_recovery_site_profiles.aspx


28 http://www.disabilityalliance.org/ibmigrate3.htm

Further reading

Resource Library – Recovery Devon
http://www.recoverydevon.co.uk

Publications by Together
http://www.scottishrecovery.net/Peer-Support/peer-support.html