





# Lived Experience Leading The Way Peer Support in Mental Health

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'Peer Support sees the person first, understands their distress and can offer true solutions that the Supporting Peer has used themselves.'

PATE

Peer Support Worker, Peer2Peer member

## Lived Experience Leading The Way Peer Support in Mental Health

Thurstine Basset, Alison Faulkner, Julie Repper and Elina Stamou

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## **Foreword and Acknowledgements**

#### Foreword

Too often, answers to the question 'How can we improve the lives of people with mental health problems?' have taken the form of a prescription for more mental health professionals. Arguments reign about exactly which professionals we need more of (doctors, psychologists, nurses, complementary therapists ...). But what such disputes obscure is the key point that mental health professionals of whatever hue do not hold the key to recovery.

To be sure, professional expertise may be valuable to many, but it is far – very far – from the whole story. There is another sort of expertise - long known by those of us who have been on the receiving end of mental health services but hitherto barely recognised by the wider mental health arena - the expertise of lived experience. The gift of hope and companionship that people, who have walked a similar path, can give each other. This is quite a different relationship to that between professional and patient, where the professional is the 'expert' and prescribes what is good for 'their' client.

Peer support is based on mutuality and a shared journey of discovery within which people help and support each other as equals, share their personal stories, teach, learn and grow together. This is a relationship that empowers each to grow within and beyond what has happened and to find a new sense of self, meaning, value and purpose in life.

Recognition of the power of peer support to transform lives and revolutionise services is not limited to the mental health arena. From breastfeeding to bullying in schools, from diabetes to dementia, head injury to heart disease, its transformational value is being recognised. In the pages of this report, in the work you have started and in your ambitious plans to develop peer-led services in the future, Together have made an enormously valuable contribution in the mental health arena. This is an important document that should be essential reading both for those of us with mental health problems who are rebuilding our lives and all who aspire to be our allies and support us in our journey.

Rachel E. Perkins OBE Freelance Consultant and Trainer Recovery - Employment - Participation Mind Champion of the Year 2010

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Peer2Peer Group -Together

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WRAP training group (Rochdale)

**Reading Resource** 

## Introduction

At **Together** we work alongside people on their journey to leading fulfilling and independent lives. We work with around 4,000 adults a month, most living with complex and recurring mental health issues.

Together's Service User Involvement Directorate (SUID) comprises of people with lived experience that develop and support innovation in service user involvement.

Together is trusted for our expertise in service user involvement, empowerment and leadership that promote wellbeing. Peer support is key in our philosophy and service delivery. We work directly with people that support peers, run peer support programmes and work in partnership with user led organisations and other key stakeholders to deliver peer support.

We brought together and facilitate the Peer2Peer Group that comprises of a core working group of user led organisations that lead on peer support in their area and an extended network of statutory, community and academic experts.

Peer support can work in a very powerful way. We know that, we've experienced it ourselves within SUID and we've seen it through our programmes and partnerships.

The University of Nottingham has developed and now runs an accredited training programme for peer support workers. This has been done in partnership with Making Waves, a service user organisation in Nottingham. In working with their local NHS Trust, The University of Nottingham and Making Waves are part of a UK-wide network of NHS Trusts that are employing peer support workers to work in mental health services.

**The National Survivor User Network (NSUN)** is a mental health service user led organisation established in 2007 following the recommendations of the 'On Our Own Terms' report (Wallcraft et al 2003). Its mission is to engage and support mental health service users in England. It aims to facilitate links between user groups and individuals, broker access to service users by policy-makers and provide training in leadership, organisational skills and campaigning. Activities include running regional networks, commissioning research, supporting service user/carer policy involvement and running a national Service User Involvement Workers Peer Support Development Group. NSUN is committed to promoting and developing peer support across England at a local, regional and national level.

In the summer of 2010, Together commissioned two pieces of work:

Using Personal Experience to Support Others with Similar Difficulties: A Review of the Literature on Peer Support in Mental Health Services by Julie Repper and Tim Carter, University of Nottingham.

A Helping Hand: Consultations with Service Users about Peer Support by Alison Faulkner and Thurstine Basset, independent consultants working for Together.

Building on these pieces of work, this report was then produced:

Lived Experience Leading The Way: Peer Support in Mental Health by Thurstine Basset, Alison Faulkner, Julie Repper and Elina Stamou, Peer Support Development Manager, Together.

Lived Experience Leading The Way – Together ©

#### All three reports can be accessed at: www.together-uk.org

N.B. We have used the term 'service user' as a working term in this report whilst acknowledging that there are other terms such as 'volunteer', 'survivor' or person with 'lived experience' that people use to describe the aspect of identity linked to their experience of mental health issues. We acknowledge that the best way forward is for each person to be able to use and be referred to by the term that they feel most comfortable with.

## History and background of peer support

'Peer Support has a long and honourable history in mental health. Fellow patients and service users have always provided invaluable support to each other, both informally and through self-help and activist groups' Jackson (2010)

As Jackson notes, informal peer support or mutual support has long been seen to take place wherever service users come together – in inpatient wards, day centres and drop-ins and in service user groups. At the core of peer support is the need to feel truly understood, to find that you are not alone with your experiences of distress or madness. Finding that others have had the same or similar experiences can lead to a sense of genuine empathy and shared understanding, to reassurance and hope.

'Some people had discovered the value of shared experience through self-help groups addressing a particular aspect of mental distress, such as sexual abuse or depression, whilst others had discovered it through voluntary sector projects, dropins or day centres, where they had met 'like-minded' people.

As much as the frequency with which this theme recurred, it was the strength and passion with which it was expressed that caused it to stand out for us. For some people, finding others who had experienced something similar to themselves was in itself important, because they had previously felt alone with their experiences, and now were able to find reassurance and affirmation of their experiences in the company of others.' Faulkner and Layzell [2000, pp 92-3]

Similarly, coming together in adverse circumstances, as in the case of some inpatient wards, can create a sense of camaraderie and can be ultimately more supportive than the treatment on offer (Walsh and Boyle 2009). Finally, coming together to campaign for alternative or better services or against enforced treatment can be both supportive and empowering (Lindow 1994).

The long and honourable history that Jackson refers to includes the Alleged Lunatics' Friends Society (1845 – 1863). In the 20<sup>th</sup> Century, the 1970s saw campaigning groups such as the Mental Patients Union, followed by Survivors Speak Out in the 1980s and UKAN (United Kingdom Advocacy Group) in the 1990s. These groups or organisations were rights-based in their approach, but an element of peer support, often quite spontaneous and informal in nature, was also at the root of their day-to-day activities.

In related fields, organisations like AA (Alcoholics Anonymous) have been constructed entirely around peer support and the ability of people with alcohol problems to use their own expertise to assist each other. There are many other examples across the broad spectrum of health and social care. Mental health peer support has also developed along more formal lines over the years. For example, groups have been set up with the expressed intention of enabling people to meet and support each other in facilitated or non-facilitated self-help or mutual support groups. Networks of self-help groups, such as the Hearing Voices Network and MDF: The Bipolar Organisation, both user-led organisations, have been established to raise awareness of and to promote self-management strategies and mutual support for managing specific conditions or symptoms. The Hearing Voices Network started in the late 1980s and was inspired by the work of Marius Romme and Sandra Escher:

'Hearing Voices groups are typically, a number of people who share the experience of hearing voices, coming together to help and support each other, they exchange information and learn from each other, they share the same problems and may have similar life situations. Sometimes the group may include relatives and carers of people who hear voices.

The purpose of hearing voices groups is to offer a safe haven where people feel accepted and comfortable. They also have an aim of offering an opportunity for people to accept and 'live with their voices', in a way that gives some control and helps them to regain some power over their lives.' [www.hearing-voices.org]

MDF: The Bipolar Organisation was established in 1983 and one of its core developments is to establish a network of self-help groups.

A development that took place in the 1990s, which parallels the peer support worker of today in some respects, was the increase in employment of service users in such posts as 'user involvement development worker' or 'consumer advisor'. Some of these posts were directly responsible for developing service user involvement in organisations but some were involved in direct service provision (Relton and Thomas 2002). This was largely seen as a positive development, but increasingly people fulfilling these roles became aware of the pressures on and dilemmas surrounding the positions they found themselves in.

Often employing organisations anticipated that employing a single worker could solve complex issues of user involvement. Burnout and stress were commonplace and the need for organised support and supervision of these employees became paramount. Organisations, even mental health organisations, were not always familiar with employing people with mental health problems and some did not deal well with situations in which a person became distressed in the workplace or went off sick.

It was in the wake of these experiences that Rose Snow and others organised the 1<sup>st</sup> National Conference of Survivor Workers UK in 2000 (Snow 2002). This was an innovative and most welcome initiative with a clear and important acknowledgement that mental health workers have mental health problems. The report from this conference is essential reading for any individual or organisation that wants to develop mental health peer support services.

The 1990/2000s also saw the setting up of small but increasingly powerful numbers of service-user led organisations across localities, such as CAPITAL in West Sussex which started in 1997 and Making Waves in Nottingham founded in 2003. These are but two examples, and in 2003, the Sainsbury Centre for Mental Health published a report on behalf of the User Survey steering group (Wallcraft et al 2003). This report detailed a survey of the mental health service user movement in England. It covered 318 service user groups, representing some 9,000 service users and found that 79%

of local and national service user groups were engaged in self-help and mutual support. This work led to the founding of NSUN (National Survivor User Network) in 2007.

In 2010, there is a greater acceptance that service user expertise has something very useful to offer and that peer support can be an effective part of mental health services. People who have lived experience of mental health issues have been increasingly involved as trainers and educators in both national and local awareness raising and anti-stigma campaigns. Their status as 'experts by experience' is now acknowledged, alongside that of the various mental health professions.

Often building on work already done in the USA, Canada, Australia and New Zealand, the UK is embracing peer support in various new and innovative ways. The Scottish Government recently commissioned peer support workers after a successful pilot scheme (McLean et al 2009) and there are currently about twenty peer support workers in post across Scotland.

In England, an increasing number of NHS Trusts are employing peer support workers. For example, Cambridgeshire and Peterborough NHS Foundation Trust are committed to training and employing 80 peer support workers in their first wave. These NHS Trusts have recently formed themselves into a network. In Wales, the Mental Health Foundation, working in partnership with MDF: The Bipolar Organisation and Cardiff University are currently (2009-2012) running 60 courses and hope to reach 900 people with mental health problems. The courses are about self-management but in addition peer support networks for all course participants are being developed.

(For information in this part of the report, thanks are due to the survivor history group – www.studymore.org.uk/mpu.htm)

(For recent developments on peer support in USA, see Daniels et al (2010) and in New Zealand, see Knowledge Institute (2009) for a report by Wellink on the characteristics of good peer support)

## Types of peer support

'Peer support means receiving support and understanding from someone who's equal, has had similar (not necessarily the same) experiences and insight.' Peer2Peer Group

'Peer support came in with the first group when we met about 13 years ago, becoming supportive, exchanging phone numbers – it evolved rapidly.' CAPITAL Group

'Peer support is a system of giving and receiving help founded on respect, shared responsibility and mutual agreement of what is helpful.' Mead et al 2001

'When someone has spent an awful long time being misunderstood in the mental health system, peer support is like a breath of fresh air and can be lifesaving. I have found, during frequent stays in hospital, that the contents of my file seemed to be more important than my presenting state of mental health. 90% of the time I just want to talk to someone who can truly understand and can offer solutions they used themselves to overcome similar experiences – it is liberating. I am not a diagnosis, I am a human being and as such I am more important than my diagnosis. Peer Support sees the person first, understands their distress and can offer true solutions that the Supporting Peer has used themselves.' Peer2Peer Group member

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Peer support is about people with lived experience supporting each other in their wellbeing journey. It may be:

- Informal and usually provided on a voluntary un-paid basis
- Formal or as it's also called 'intentional' where the peer support worker is usually paid
- Peer-led or Staff/professional-led
- Run by a service user-led group (usually part of the fabric of their work) or within a statutory environment (for instance an NHS Trust)
- An initiative, programme, project, service, group or organisation
- Provided in various contexts, such as: peer support in acute admissions, in a crisis centre, in the community, in a day centre, in forensic services, offering peer support training, peer support brokerage, 24-hour peer support service.

Bradstreet (2006) talks about 3 types of peer support:

- (a) informal/unintentional and naturally occurring peer support
- (b) participation in consumer or peer-run groups/programmes, and
- (c) use of consumers/service users as paid providers of services formal or intentional peer support.

There is considerable, if often anecdotal, evidence of informal/unintentional and naturally occurring peer support in hospitals and other mental health services. As regards participation in service user groups, there is evidence that these groups often start out with no specific aim to provide peer support but that this support evolves naturally from the start and is eventually incorporated into the overall aims of groups. The employment of service users as peer support workers is increasingly a hot topic in relation to mainstream mental health services in England and Scotland.

In our work over the summer of 2010, Together, the University of Nottingham and NSUN have looked at two types of peer support:

- Peer support that comes from participating in service user or peer run groups
- Peer support that comes from the employment of service users as paid providers of services

## **Current policy**

In England, it is clear that the provision of peer support has grown due to the development of Recovery-focused mental health services. Generally it is acknowledged that peer support is one important way of promoting the principles of Recovery.

The National Service Framework for Mental Health (Department of Health 1999) stated that people with mental health problems could expect services that involve service users and their carers in the planning and delivery of care. New Horizons: a shared vision for mental health (Department of Health 2009b), delivered by the previous Government underlined the fact that people with mental health problems are able to run their own lives, participate in family and community life, and work productively to earn their living and contribute to the economy, to varying degrees.

Rising to this challenge, mental health service users are increasingly demonstrating that they have a role to play in both shaping and delivering mental health services. The current 'recovery-based' focus to services demands that service users are placed in a central position with regard to service planning and delivery.

The Sainsbury Centre for Mental Health (2009) outline ten key organisational challenges for implementing a recovery-focused approach. Challenge no. 8 'Transforming the workforce' states that working in partnership with service users will lead to a change in the make up and composition of the workforce:

'As services become more truly focused on service users' needs and accept the value of 'lived experience', so there are obvious implications for the composition of the workforce. Professionals will remain important, but they will have to recognise that their contribution needs to be made in a different way, acknowledging service users' self-defined priorities. By contrast, we expect to see a greatly expanded role for 'peer professionals' in the mental health service workforce of the future. We recommend that organisations should consider a radical transformation of the workforce, aiming for perhaps 50% of care delivered by appropriately trained and supported 'peer professionals'.'

The current key government policies of personalisation and choice are strongly aligned to peer support (Putting People First: Planning Together – peer support and self-directed support – Department of Health – 2010b). The provision of peer support will be instrumental in making these policies a reality. Bromley Mind has produced a helpful report that links peer support with person-centred planning and bridge building. (Duffield and Rendell 2009)

The McKinsey Report (DH 2009a) indicates that major cost efficiencies can be made through increased service provider productivity and workforce reorganisation; adjusting the skill mix of frontline staff. Involving people more closely in directing their own care has been shown to contribute to significantly lower demands on health services over the longer term (Wanless 2002).

Peer support has been identified as a key facilitator across a range of health and social care strategic agendas, including mental health recovery (Social Care Institute for Excellence et al 2007), self care (DH 2006) and personalisation (DH 2010b). Skills for Health (2009) identifies new roles and new sets of competencies that would be necessary, in order to implement the Personalisation agenda, in understanding, advocating for and accessing care across health and social care boundaries.

The White paper, Equity & Excellence: Liberating the NHS (Department of Health 2010a) views GP Consortia commissioning as the mechanism for bringing down costs and being responsible for actively pursuing the QIPP (Quality, Productivity, Innovation and Prevention) agenda. Patients are to be the driving force for improvement through increased access to quality data and choice, with payment for NHS services linked to patient outcomes, rather than service activity.

However, to sound a note of caution, the personalisation agenda can sometimes appear individualistic with little sense of a shared agenda and solidarity, and with an emphasis on individual peer support rather than peer or mutual support within groups.

The social inclusion agenda has also led to pressure on day services and drop-in centres to be more individualised and thereby to lessen their role in helping service users to come together for strength, direction and empowerment. Of course it is important that service users receive care and support packages that are tailored to their unique individual needs. But it is most often a collective sense of being in the same boat with accompanying solidarity and empowerment that forms the basis of peer support and is very important in enhancing individual support and benefits.

It may be helpful here to reflect on some of the costs that arise from mental health problems and the possibility that peer support could help to reduce these.

## **Cost of mental health**

The costs associated with mental health are significant, for example:

The Sainsbury Centre for Mental Health (2003) has estimated that mental health problems cost England over £77 billion a year through the costs of care, economic losses and premature death.

McCrone et al for The Kings Fund (2008) confirmed the major adverse economic impact of poor mental health, which currently outstrips the direct NHS and social care service costs of supporting people with mental disorders.

The Social Exclusion Unit (2004) reported that adults with mental health problems are one of the most excluded groups in society. Although many want to work, fewer than a quarter actually do – the lowest employment rate for any of the main groups of disabled people. Over 900,000 adults in England claim sickness and disability benefits for mental health conditions.

New Horizons: a shared vision for mental health (Department of Health 2009) states that no other health condition matches mental ill health in the combined extent of prevalence, persistence and breadth of impact.

In this report, we are suggesting that peer support is both efficient and effective and delivers good value for money as costs can be reduced through maximising the expertise of peer support workers. Later in this report, we will outline some evidence to back up this assertion.

### Principles of peer support – the essence of peer support

It seems to us that the essence of peer support is contained in these 12 principles. For peer support to exist and flourish, it must contain at its root the principles of:

- ✓ Mutuality
- ✓ Solidarity
- ✓ Synergy
- ✓ Sharing with safety and trust
- ✓ Companionship
- ✓ Hopefulness
- ✓ Focus on strengths and potential
- ✓ Equality and empowerment
- ✓ Being yourself
- ✓ Independence
- ✓ Reduction of stigma
- ✓ Respect and inclusiveness

These principles are important and may be compromised when peer support is provided by mainstream/statutory mental health services. We would argue that to keep this essence of peer support, there is a strong need to maintain links with voluntary sector and service-user led groups. This is, arguably, where peer support both develops and is rooted.

Modern mental health services are in theory based on these principles and should have no trouble in adhering to them. However, traces of past attitudes often emerge to both block and compromise the progress of peer support. It is important that mental health services are able to be open and engage in honest dialogue with user led and voluntary sector partners. The service user voice is often linked to a solidarity and shared experience that wants to break through conventional barriers and speak out in bold and assertive ways that may jar with conventional service provision. Peter Campbell's poem below is but one example.

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#### **The Mental Marching Band**

You'd better whet your whistles For the Mental Marching Band For we're making a wee comeback And it's speaking through the land. And we'd laugh you to distraction About the Mental Marching Band.

There's Danny Ogenkenyu On the bagpipes by the way. And when he's took his Lithium Sweet Jesus can he play. You can denigrate the madness The song won't fade away From the Mental Marching Band.

We'll all be out and running When the storm breaks.

Down the House of Commons Wi' our fruitcake. You'll have to take your medicine then Just for the music's sake And the Mental Marching Band.

We'll not be taking prisoners Under blood red skies. We've had too much confinement In our own lives. We're getting our own World War out That everyone survives. Thanks to the Mental Marching Band. Let's hear it.

Reproduced with permission from Peter Campbell Brown Linoleum, Green Lawns, Hearing Eye (2006)

# Peer support from participating in peer run groups – benefits and challenges

As already indicated, there is a long-standing tradition of peer support within service user groups and organisations. For example, as previously mentioned, Wallcraft et al (2003) identified that 79% of local and national service user groups were engaged in self-help and mutual support. This was the most frequent activity reported by the groups in their survey.

Munn-Giddings et al (2009) comment:

'A key feature that distinguishes the culture and governance of User-Led Organisations from other types of voluntary organisations is the type of knowledge on which these organisations are based and on which they develop. Their knowledge base derives predominantly from direct individual and collective experience of health or social care conditions. They are mutual aid rather than philanthropic organisations, in the sense that the service is based on peer support rather than charitable giving.'

Malpas and Weekes (2001) report:

"A favourable aspect of attending the drop-in was the peer support respondents were able to grant each other. 82% indicated that this was the main reason for their continued attendance. The support people offered and received from one another was the primary factor affecting the improvement and stability of drop-in users' mental health.

'Coming here has helped with communication on a one-to-one basis, I was very unsure before. I find that helping others takes the focus off my problems and I gain confidence'."

The benefits of this type of support are many and in our own work 'A Helping Hand: Consultations with Service Users about Peer Support' – Faulkner and Basset (2010), we conclude that the benefits are:

- Shared identity
- Increased self-confidence
- The development and sharing of skills
- Improved mental health and wellbeing, accompanied by less use of mental health and other services
- An increased role in information sharing and signposting
- A feeling that peer support challenges 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

The Pyramid of Peer Support (see Figure 1) is a useful way of looking at peer support. The essence of peer support begins with informal and naturally occurring support, which is also normally the bedrock of service user groups. In essence, service users use their own knowledge and expertise to help both themselves and others. This help has the authenticity of being rooted in personal experience, which is acknowledged as the most powerful and effective way of learning.

## Figure 1 - Pyramid of Peer Support

(with thanks to Rochdale WRAP group)



The base of this pyramid is crucial and must be strong and robust if peer support, in all its various forms, is to flourish. As peer support becomes more structured and organised, it can become more focused and helpful but care must be taken that its essence is not lost within more formal and professional structures.

Other benefits of peer support within service user organisations and groups are a feeling of acceptance, solidarity, belonging, friendship, decreasing isolation, hope and inspiration, learning, increased motivation and an ability to overcome problems that traditional services have not helped with:

'Being involved felt good but to do so effectively living in West Sussex meant that travelling was essential. Cognitive Behavioural Therapy with a psychologist had

previously failed even to get me to walk down my road alone. However with the motivation to get to particular places and the feelings of support from other CAPITAL members, gradually my confidence grew so that I could make increasingly complicated journeys alone. Within two or three years, travelling had ceased to be a problem for me.' (Ockwell 2010, p135)

The challenges for service user organisations in providing peer support revolve around:

- Maintaining independence
- Being seen as credible
- Remaining flexible and avoiding red tape
- Getting too involved without sufficient training
- Challenging the existing culture
- Needing funding
- The benefits system.

'It is important to acknowledge the different views in relation to peer support that arise in different service user and voluntary sector groups: about key issues such as payment and professionalisation. Ultimately, peer support arose from people wanting to create their own support networks; any plans to formalise it from within statutory services need to acknowledge that pre-existing expertise.' (Faulkner and Basset 2010)

## Peer support from the employment of service users as paid providers of services – benefits and challenges

Repper and Carter (2010) in our Together/University of Nottingham/NSUN literature review, which is primarily concerned with peer support workers employed within traditional mental health services, conclude:

'Clearly there has been exponential growth in the employment of peer support workers (PSWs) in the US, Australia and New Zealand over the past decade and more recently this expansion has spread to the UK. The focus of all recent mental health policy upon Recovery focused practice appears to be a key driver for these initiatives.

The employment of peer support workers is seen to be a vehicle for the transformation of mental health services and research appears to be bearing out these policy aspirations. Trials show that at the very least, PSWs do not make any difference to mental health outcomes of people using services.

When a broader range of studies is taken into account, the benefits of PSW become more apparent. What PSWs do more successfully than professionally qualified staff is promote hope and belief in the possibility of Recovery, empowerment and increased self esteem, self efficacy and self management of difficulties, social inclusion, engagement and increased social networks. It is just these outcomes that people with lived experience have associated with their own Recovery; indeed these have been proposed as the central tenets of Recovery: Hope, Control/Agency and Opportunity (Repper and Perkins, 2003; Shepherd et al, 2008). In addition, employment as a peer support worker brings benefits for the peer support workers themselves in every reported evaluation. The experience of valued work in a supported context, permission to disclose mental health problems, which are positively valued, all add to self-esteem, confidence and personal Recovery. Experience of peer support working also increases chances of further employment, personal development and achievement of life goals.

Whilst there is some evidence that PSWs can challenge discrimination, promote positive language, emphasise strengths and possibilities, it is also clear that they cannot do this alone. The whole system needs to support the change through changes in language, practices, procedures and policies consistent with a Recovery-focused approach.

Recovery Innovations in Arizona is testament to the wholesale change in culture brought about by a focus on Recovery; a Workforce comprising over 50% PSWs is a large part of this change but there were simultaneous changes in policies (e.g. no restraint) in staff training and roles (see recoveryinnovations.org) and in service structures (e.g. Recovery Education Centre to provide accredited training rather than therapy; introduction of a peer run crisis centre - The Living Room) and in procedures (training in Wellness and Recovery Action Planning (WRAP) for everyone using the service).

On the whole, the literature reflects a movement in its early stages of development, particularly in the UK. Whilst full of promise and potential, this initiative needs careful nurturing and shared learning so that early pilot sites pass on their learning and others can develop it further. This way Peer Support Workers are not put under unnecessary stress; mental health services evolve gradually with attention to the needs of existing staff, and people receiving support achieve optimal outcomes.'

Whilst the main impact of peer support is on the service user and the peer support worker, it is helpful to consider the wider impact that benefits from peer support has on families, communities and the wider mental health system as a whole.

## Social and economic benefits of peer support - increased community involvement

Nelson et al (2007) found increased community integration for service users involved with consumer/survivor initiatives. They also found increased quality of life in relation to daily living activities and a significantly greater involvement in work or participation in education. This was accompanied by lower levels of symptom distress.

Forchuk et al (2005) found that service users, who received peer support, demonstrated an enhanced quality of life related to social relations.

## Social and economic benefits of peer support - fewer hospitalisations

Forchuk et al (2005) found that service users, who received peer support, were discharged from hospital an average of 116 days earlier per person.

Lawn et al (2008) evaluated an Australian mental health peer support service, which provided hospital avoidance and early discharge support. They found that in the first 3 months of operation over 300 bed days were saved. In addition, they also found

that peer support has the potential for encouraging a greater focus on recovery in both the culture and practice of mental health services.

Chinman et al (2001) compared a peer support outpatient program in the USA with traditional care and found a 50% reduction in re-hospitalisations compared to the general outpatient population and only 15% of the outpatients with peer support were re-hospitalised in its first year of operation

Min et al (2007) studied a peer support program over a 3-year period. They found that participants receiving peer support had longer periods of living in the community without re-hospitalisation than a comparison group. 73% of people in the comparison group were re-hospitalised versus 62% in the peer support group.

Clarke et al (2000) found in a random control trial that when assigned to either an all peer support worker or an all non-consumer community team that those under the care of peer support workers demonstrated fewer hospital admissions. The average number of days in the community until first hospitalization was 339 days for clients of the non-consumer team and 426 for clients of the peer support worker team. Significantly more clients served by the non-consumer team (n=31) as compared to the consumer team (n=21) were hospitalized. In addition, significantly more clients served by the non-consumer team (n=25) as compared to the consumer team (n=15) visited an emergency room.

Peer Support services are also proven to be extremely cost-efficient. The cost per day for one acute mental health hospital inpatient has been calculated to be £259 (Healthcare Commission 2008). By comparison, the Leeds Survivor-Led Crisis Service (see www.lslcs.org.uk) successfully supports people at £180 per day.

Whilst many benefits of peer support work have been established, there are also a number of challenges that need to be faced. Challenges for peer support workers can be summarised as:

- Issues about boundaries and disclosure
- Their relatively powerless position within mental health services
- Stress generated as a consequence of their work
- Issues of responsibility, accountability and governance
- A clear need for strong and relevant support, supervision and training.
- A further need for clear roles and job descriptions.
- The culture of mainstream services may inhibit the effectiveness of the role.

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'Being a peer support worker gives me an enormous boost to my self-esteem. It's a great feeling to go home and know that you've brightened up another person's day. I realise that I can make a contribution and be of value and this is quite something in a society that, in my experience, generally sees people with mental illnesses as worthless.

When I was first ill about 14 years ago, there was no organised peer support. But, when in hospital, I often found I was sitting with a small group of patients discussing our situation and generally helping one another. I guess that's where I first got the idea that I might have something to offer as a peer supporter.

Some time later when I was no longer in touch with mental health services, I worked out some activities and exercises that helped me keep well. A lot of these were artsbased and this is how I currently offer peer support in a local acute ward. Through the acute care forum, that I had been invited to join, I had put forward the idea that I should run art exercises on the acute ward. These exercises help patients to focus on something and are also fun, as I believe laughter is a great medicine. Sometimes, when you are not very well, art is an easier way to communicate than talking. The art exercises are evaluated and the feedback is very positive, which is a great tonic to me.

Patients on the ward get to know me through the regular art exercises and in time they talk to me about their issues and problems. I help them tune back into reality. They know I have been a patient too and we speak the same language. I have also been able to talk with staff and give them some insight into what it is like to be a patient on an acute ward. I would rather be working alongside staff than working against them. I think I can sometimes be a bridge between patients and staff. I believe that peer support is exciting and opens things up.

I work as a volunteer, but that's my choice. I feel more independent not being paid. It is great to be able to use my experience to help others and through helping others I am indeed helping myself. This is the essence of peer support – I support you today – tomorrow, you support me.'

Ruth Le Goff - Peer Support Volunteer Berkshire Healthcare NHS Foundation Trust

"Peer support offers something that can go beyond the professional support and therapy offered to people during crisis. Seeing a person who has been there, and is able to tell the tale of their own recovery, offers real hope to individuals who may not have any at that particular point in their life. The feedback from the peer support project that has been running in Berkshire has been extremely positive and patients have welcomed the input that has been offered. The peer volunteer is now well integrated with the ward staff and the patient group, and all look forward to her visits."

Gwen Bonner - Nurse Consultant East Berkshire Inpatient Services Berkshire Healthcare NHS Foundation Trust

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### The Future – recommendations for future work and research

Please find below a number of recommendations that we feel will lead to an increasing recognition and acknowledgement amongst stakeholders of the importance of peer support in its various forms and the vital contribution that it has to play in improving outcomes for individuals who experience mental distress.

Peer support in service user groups:

- There is a need to allow and enable more informal peer support to flourish both independently and within service user-led groups and programmes. In the current economic climate, some service user organisations are feeling under threat. They are clearly the bedrock upon which peer support is based. Without this firm connection to the grass roots, peer support cannot flourish.
- Where peer support is more formal and involves some paid peer support workers, it is important to avoid the 'professionalisation' of peer support.

Peer support that involves the employment of service users as paid providers of services

- There is a need to strengthen the position of employed peer support workers in services through training, support, supervision and sufficient resources.
- There is a need to ensure that peer support perspectives are built into the new NHS commissioning arrangements.

Training

- Training is required for mental health staff to increase their awareness, receptiveness and support for peer support of all kinds particularly where peer support workers are joining mental health staff in teams or services
- Accredited training programmes for peer support workers need to be further developed and established e.g. in Reading and Nottingham

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### **Examples of Accredited Peer Support Training**

Reading Resource is a Together service, which runs a full peer support programme with a training programme for peer support workers. The Open College Network accredits the programme. This programme is also accessed by other services (for example, Sussex Oakleaf) as a training resource for people who use their services and who wish to take on a peer support role.

Nottingham University and Making Waves have collaborated to develop and now run a training programme for peer support workers. This programme is accredited by Sheffield Hallam University

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#### Research

- It would be helpful to examine the position of all types of mental health workers with lived experience – considering their support needs and what resources are available to meet these needs. At what point will they develop sufficient confidence to use their own experience in their practice both explicitly and implicitly to make them indistinguishable from peer support workers? It is interesting to reflect on whether such a point will be reached and if so, what effect it might have on the essence of the peer support programme?
- Further work is needed to explore and describe the emergence of peer support workers and to consider what helps and hinders the emergence and successful application of these roles both within statutory environments and user led groups
- It is vital that we explore the development and potential use of measures and key performance indicators that are both appropriate for peer support and are able to effectively measure its unique outcomes
- It would be helpful to explore the key role of carers/family members in relation to peer support

#### Breadth of perspective

• There is a need to promote the importance of service user knowledge/expertise and service user led organisations as this lies at the

heart of peer support (building on existing work such as that by Branfield and Beresford - 2006)

- We need to keep the focus broad and not just on mental health and learn from other fields where peer support is well-established – there is a lot to learn about peer support from the fields of physical disability, learning disability, long-term illness and the youth work sector
- It is vital to include all users of mental health services and be diverse in the application of peer support there is a lot to learn from Black and Minority Ethnic mental health organisations about peer support

Building alliances and partnerships

• Our final point is that peer support of all kinds only works when there is a spirit of collaboration and partnership. We strongly recommend active and ongoing cooperation between service user groups, voluntary organisations, service providers in the statutory sector and commissioners of services to help turn shared vision into concrete practice.

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