A Helping Hand
Consultations With Service Users About Peer Support

Alison Faulkner and Thurstine Basset
30th September 2010

Elina Stamou
12 Old Street
London EC1V 9BE
0207 780 7358
elina-stamou@together-uk.org

www.together-uk.org

A Helping Hand
Consultations With Service Users About Peer Support

By Alison Faulkner and Thurstine Basset

Introduction

As part of Together's strong commitment to service user involvement and peer support, they commissioned Thurstine Basset and Alison Faulkner to undertake a piece of work with a view to informing and assisting Together in making a case for peer support.

This is a report of the discussion groups with service users during the summer of 2010. The aim of these groups was to explore people's views and experiences of peer support in different settings, and to explore with them the benefits and challenges of peer support.

Together wanted to obtain a snapshot of 'peer support in action' over the summer of 2010, trough consulting people from their own networks. These networks are rooted in the voluntary and independent sector and made up of service users who have significant knowledge and expertise in relation to peer support.

For this report, Together would like to thank Thurstine Basset, Alison Faulkner, the Peer2Peer Group, CAPITAL, Borough Wide User Forum, Rochdale WRAP training group and the Together Reading Resource Centre.

Outline

Thurstine Basset (TB) and Alison Faulkner (AF) carried out a total of five consultations with service users exploring their views about the role and value of peer support. From the original Peer2Peer group meeting at Together, three further groups were contacted, one of which resulted in two separate consultations. The final five groups were as follows:

1. **Peer2Peer group meeting at Together.** A group of cross-disability service users with some professionals from across England convened by Together, all of whom are involved in developing or providing peer support in different ways in their localities. [14 people]

2. **CAPITAL (Clients and Professionals in Training and Learning) in West Sussex.** A countywide service user group, which operates across West Sussex. Originally set up to develop and provide training by service user trainers, this group has been running for 13 years and according to one of the founder members, has been providing peer support informally from the start. [20 people]

3. **Rochdale (1): the Borough Wide User Forum (BWUF)**. A borough wide group of service users and carers, this group has a campaigning role (in relation to improving services) and members sit on local committees and forums. In Rochdale at present, there are plans to develop a more formalised version of peer support. [9 people]

4. **Rochdale (2): the WRAP (Wellness Recovery Action Plan) training group.** Members of this group were involved in providing WRAP training locally; they were aware of the plans for developing intentional peer support. [3 people]

5. **Reading: peer support workers at Reading Resource**. A service provided by Together. These were all trained to provide peer support to people attending and making use of services provided by Resource; one member was providing peer support at a local Wellbeing group for mothers and toddlers. [6 people]

The five groups resulted in a total of 52 service users being consulted about peer support. The gender breakdown was 37 women and 15 men.

Direct quotations in this report from these five discussion groups are identified as follows:

P2P – Peer2Peer
CAP - CAPITAL
BWUF – Borough Wide User Forum (Rochdale)
WRAP – WRAP training group (Rochdale)
RR – Reading Resource

Methods

Each group discussion was approached in a similar way: facilitated by AF or TB with a series of questions about peer support, which included:
- what does peer support mean to you?;
- what are the benefits and challenges of peer support?; and
- what have you gained from peer support?

Contemporaneous notes were taken and swiftly written up to ensure that as much as possible of the discussion could be recorded for the purposes of writing this report.

Findings

I. What does Peer Support mean to you?

Responses to this question were influenced by the nature of the group and their experiences. Two (CAPITAL and BWUF) were county or borough-wide service user groups meeting on a regular basis to engage in activities relating to campaigning, training, user involvement and the improvement of services. Members of both these groups saw peer support primarily as a vital part of their group's activities and something that occurs spontaneously and informally between group members.

Conversely, peer support workers at Reading Resource and members of the Rochdale WRAP group saw peer support primarily as an intentional activity occurring on a one-to-one basis. They saw peer support as a more formal relationship between two people where one is offering support to the other from a basis of shared experience. The Peer2Peer group represented a combination of these views.

Informal or group peer support
Members of BWUF saw peer support as something that occurs naturally, spontaneously, an informal part of being in a group such as this. A few were definitely averse to ideas about

formalising peer support and three in particular said people should not be paid to provide peer support as this would automatically change the nature of the relationship – it would no longer be 'peer' support as one would then be a paid professional.

Similarly, CAPITAL members talked of peer support as something that occurred naturally and had been there from the start of their group, some 13 years ago. In their view, any formalisation of peer support should come '*from the bottom up, not top down*'. They described themselves as '*friends with something in common*'.

> *It is a group of people supporting each other providing what is wanted in so far as they can.* [CAP]

Members of these two groups talked of the importance of them all being 'in the same boat', or on a level with each other, the sense of solidarity that being in the group gave them. Both groups also mentioned the importance of coming together with a shared cause: that of influencing and improving local services.

Formal (or intentional) peer support

Members of the group meeting at Reading Resource were peer support workers and had received training to provide peer support within the Resource centre and at a local Wellbeing group for mothers and toddlers. They are employed on a sessional basis at the centre (3 hours per session) and within that can offer a maximum of 15 minutes support on a one-to-one basis. The Rochdale WRAP group were people involved in providing WRAP training, but who had also had some input into local developments concerning intentional peer support.

> *It is a helping hand – from someone who has the right kind of experience, has been through something similar* [WRAP]

> *One person who is starting out on a journey being helped by someone who has completed their journey* [P2P]

People with experience of formal or intentional peer support inevitably had more to say about the structures surrounding it: the training, support and supervision as well as about the role and relationship between supporter and supported. They valued the training they had received and appreciated the boundaries they could place around their role as peer support worker.

II. Benefits of Peer Support

A shared identity

Across all five groups, people talked of the value of being alongside people who have had similar experiences: the feeling of being truly understood, of not having to hide or pretend about mental health problems or experiences, a sense of genuine empathy. People described the value of being accepted into a safe, non-judgmental environment (whether group or individual), where 'you can be yourself'.

> *There is a level of acceptance, you feel so accepted. We all have our idiosyncrasies but there is a terrific level of acceptance. I feel so comfortable coming in here.* [CAP]

Many people also mentioned the value of feeling reassured, less isolated or alone with their problems, just by finding other people had similar experiences.

You are not so alone - you realise that a lot of people have gone through similar things [RR]

You often feel reassured – you can feel isolated if you think no one else has had similar experiences. [WRAP]

You sometimes think that what you do is weird and a bit freaky but when you describe it to CAPITAL members they say 'I do that too'. [CAP]

Several people described the importance of feeling able to speak openly, inspired by talking to someone who would understand because they had similar experiences. People talked of '*being able to share thoughts and feelings without fear of the consequences'* and compared this with talking to professionals less openly and more in fear of judgment.

You can be yourself…you don't have to be fake as when you deal with professionals, as they have to keep up a facade whereas peers make similar mistakes. [P2P]

When I was in hospital I got peer support from the other patients; you can talk to everyone else, have things in common. [CAP]

Self-confidence
Across all five discussion groups, people talked of gaining in self-confidence or self-esteem through their involvement in peer support, whether formal or informal.

We build each other's confidence [BWUF]

Helping others
People with the experience of providing one-to-one peer support, particularly in Reading Resource, spoke powerfully of the benefits they gained from helping others. Not only did they gain from feeling they could be of benefit to other people, but also from the opportunity for putting their difficult life experiences to good use:

It is just as beneficial to myself as it is to those who I support. [RR]

All of my experiences in life can have positive meaning [RR]

It makes all the years of my pain valuable [P2P]

Developing and sharing skills
People in all groups talked about developing their skills in different ways through peer support and involvement. In the groups, people often seemed to 'rise to the occasion' developing half-remembered or dormant skills in response to the needs of the group.

People share their skills such as they are [CAP]

There are a lot of skills round this table. What this brings is a genuine purpose to those skills. [BWUF]

In both of the county/borough-wide service user groups, people talked of developing and sharing individual skills. Some people brought skills to the group, which they then shared with others; e.g. IT skills, financial and knowledge of the benefits system. A couple of people talked of developing their skills further as a result and one had gone on to find employment in a CAB.

Each one of us contributes on a different level for the greater good. [CAP]

In the more formalised peer support settings, people talked of the training they received as a springboard for the development of their skills and confidence.

It clears the mind; you regain your skills [RR]

It gives you something to put on your CV [RR]

[it provides] work and volunteering opportunities of quality [P2P]

Several people talked of moving on…although this was also a challenge and will be covered later in this report.

The support group can be a stepping-stone for people to go on to other things. [WRAP]

Mental health and wellbeing

People in all groups felt that peer support had a positive influence on the mental health of everyone involved whether they were giving or receiving support. People in the two user groups talked of the group as a 'safety net' and a vital part of their support network.

It helps you feel that you can keep going [CAP]

Being involved has given me back an interest in something, in life, it keeps me well, has given me a sense of purpose [BWUF]

This group has kept me out of hospital. [CAP]

Those involved in formal peer support work talked of its potential to improve the mental health and wellbeing of both themselves and the people they supported.

Looking after our own wellbeing in relation to others [P2P]

The more you give peer support, the less you need it yourself [RR]

Embrace it – and the less people we shall have in hospital, or the less time they will have in hospital. They will recovery more quickly. [RR]

I hope the work I do will prevent people from getting into a worse place than they are in now [RR]

Information and signposting

Both forms of peer support were ascribed the role of sharing information and signposting to other sources of advice or support. Members of the BWUF group talked of potentially developing a greater signposting role for members with the development of their website. Those in Reading Resource mentioned that their training prepared them for providing information and signposting for people they were supporting. They saw this as a part of establishing boundaries with people.

Challenging stigma & discrimination

Several people spoke of the role of peer support in relation to reducing stigma and challenging stereotypes. For some, peer support could break down the barriers between staff and service users,

by virtue of the latter having a valued role working alongside staff.   For others, the peer support itself could play a role in raising awareness about mental health and enable people to seek help in a less-stigmatising relationship or environment.

> *It is my mission to de-stigmatise mental health. [RR]*

> *In this group it is different. Mental health is right out there – so you're not embarrassed talking about it, don't feel too protective about what you are saying. You don't feel stigmatised. [BWUF]*

III. Challenges of Peer Support

Most of the challenges discussed focused on the development of more formal approaches to peer support: the importance of training, support and supervision, employment and issues surrounding maintaining a dual identity. There were other challenges too, though, extending beyond the immediate role of peer support worker. Groups could be asked to change their role by funders or to sustain themselves against a backdrop of reduced resources. Some saw the new model of peer support to be a challenge in itself, a threat to the informal nature of peer support on offer in their own and other user groups.

Support and supervision

The importance of good ongoing support and supervision for peer support workers was mentioned many times during the course of this consultation.

> *On-going supervision for peer support workers is also needed. You need to log everything that is said. You need someone to sound off to. [WRAP]*

The provision of support was only a challenge in the sense that the need for it be recognised and adequately funded. For the most part support and supervision was seen as a positive response to some of the other challenges faced by peer support workers.

Role conflict

> *Managing those different roles, wearing different hats can be difficult [RR]*

The difficulty of maintaining a dual role – that of both service user and peer support worker – was mentioned by several people. As a service user trained to be a peer support worker working alongside professional members of staff, it was pointed out that you 'wear two hats' and may potentially have difficulty being clear about the boundaries of the role. This can create some role conflict for the individual and highlights the need for ongoing support and supervision. One person pointed out that you don't necessarily stop being a service user if you are a peer support worker – but that some people might forget that you have needs too. For another person, it was important that their skills were recognised by staff and that their identity as service user was put to one side.

Boundaries

In addition to the above, the importance of clear boundaries was highlighted in relation to confidentiality and the needs of the service user seeking support.

> *The fact that people open up to you more as a peer supporter makes the confidentiality boundaries particularly important – you need to be clear about what you would need to tell someone else. [WRAP]*

A peer may want more than you can give; training can help with this. But a person can push the boundaries… there is the potential for emotional co-dependency. This is where the importance of an umbrella organisation comes in – and training and support. [WRAP]

At Reading Resource, the peer support workers were keen to point out the value of having clear boundaries, that they could be useful in helping to maintain their role.

You can use the boundaries if you are paid in a professional way. It becomes ok to say 'no' – otherwise you could reach burnout. [RR]

Training
The importance of good training was emphasised by both the Reading Resource peer support workers and by the WRAP group. Properly resourced and accredited training can become a benefit to peer support workers who have something to put on their CV and can potentially make use of it in other contexts. At Reading Resource, they receive 8 weeks training, six of which are taught and two on placement, achieving credits at NVQ Level 2.

You have the training behind you – if you get into a situation you have that to fall back on. [RR]

Assessment and selection
In a couple of groups, people talked of the 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 sufficient training or support. They suggested that good selection procedures be used to guard against the possibility that someone still quite vulnerable could be putting themselves at risk.

Moving on…
A few people mentioned the difficulty of moving on from peer support work, due to the lack of any real career pathway. One or two people had hoped that the training and employment as peer support worker would be a springboard to employment elsewhere. In one or two cases, there had been hopes of employment in the local NHS Trust, which had come to nothing.

Funding & bureaucracy
A few people mentioned the challenge of red tape and the bureaucratic barriers to getting PSWs accepted and into inpatient wards. Barriers had been encountered in Human Resources Departments, professional advisory committees, as well as the need to go through occupational health, and to have CRB checks.   All of these result in long delays to employing people, whether on a paid or voluntary basis.

Professionalisation
One of the core challenges to the development of formal or intentional peer support is the perceived danger of over-professionalising a relationship that develops out of shared experience and equality. As mentioned above, there were differences of opinion across the five discussion groups about the role and context of peer support, with Reading Resource at one end of a 'professionalised' spectrum and CAPITAL and BWUF at the other.
People in the two user groups were concerned about the potential formalisation of peer support. In the WRAP group, too, people felt that peer support workers should not be paid.

The more professional the veneer you get, the more it might become more like being a professional… it might then lead to the service user needing someone else, e.g. a befriender to fill that more informal role. [WRAP]

The defining feature is the fact that you've had the personal experience. There should be no remuneration or you would become a professional. [WRAP]

You shouldn't be paid to do it – it's not peer support if you are paid [BWUF]

I fear that we might lose that togetherness, if we go down the route of formalising peer support. [CAP]

Clearly, the peer support workers at Reading Resource were coming at this from a different direction. They valued the training and supervision; the payment and the status afforded them. In particular, they valued the structure that they could place on the peer support relationship through the judicious use of boundaries, and felt that it gave some people permission to ask for help.

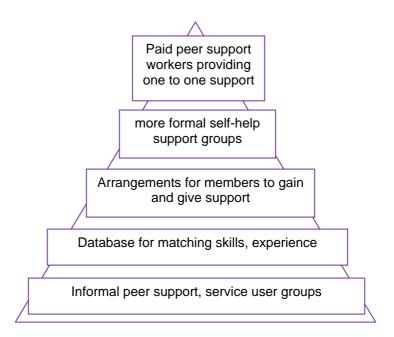*'Formalisation validates the service that's offered. It becomes a more effective service'. [RR]*

The discussions were not simply polarised around these two approaches to peer support, however. In BWUF and in CAPITAL, people talked of the potential for organising the form of peer support they offered a bit more than they did at present. This might involve a kind of 'matching process' between people's needs and skills, or a system of exchanging telephone numbers and times when people might be phoned for support. Both groups reported ongoing local discussions with local commissioners and/or providers about developing peer support in new and more formalised ways.

In the WRAP group, people talked of running or being in other self-help support groups, in which '*little pockets of peer support occur'*. Here too, it was felt that mutual support groups were best left alone and not interfered with by professionals as they can lose their role and value for members. Toward the end of this group, the discussion developed into conceptualising a peer support pyramid (see Figure 1), with group-based informal peer support at the bottom and more formal arrangements at the top, where a smaller number of people are trained and inducted to provide it on an individual basis.

In the BWUF, it was suggested that a more formalised version of peer support might be appropriate in times of crisis, when a person is in direct contact with services and might benefit from a one-to-one relationship with a peer.

Figure 1 - Pyramid of Peer Support
(with thanks to Rochdale WRAP group)

Concluding Comments

The Pyramid of Peer Support presents 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.

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 these more formal and professional structures.

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.

The challenges are mostly associated with offering more formal peer support where the need for adequately resourced support, supervision and training was stressed.

Some people gave examples of peer support workers struggling because of insufficient training and preparation. Issues of role conflict and the importance of clear boundaries arose in the groups. Official red tape and bureaucracy can be a barrier. There is no real career pathway for peer support workers, but also there are concerns that an over-professionalisation of the peer support worker role might lead to it losing its basic essence.

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 professionalization. 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.

Despite these challenges and concerns, the benefits of peer support (in all its forms) were clear, and there was a strong feeling that peer support is essentially a very valuable activity. It is important that it should be recognised as such and fully supported in its growth, which should always be bottom-up, watering the roots of peer support to enable it to grow in a strong and robust way.