

The Freedom to be, the Chance to Dream: Preserving User-led Peer Support in Mental Health

Alison Faulkner and Jayasree Kalathil
Commissioned by Together, 2012

www.together-uk.org



Contents

Foreword	3
Acknowledgements	4
Summary of the report	5
1. Introduction	9
1.1. Key research questions	9
1.2. How the work was done	10
Limitations of the study	
1.3. The survey	11
Demography	
Context and nature of peer support	
Description of peer support groups	
1.4. Telephone interviews/visits	14
Peer support projects interviewed or visited	
Organisational base	
Funding	
Membership	
Activities	
2. Peer support: what does it mean?	19
2.1. Who is a 'peer'?	19
2.2. Values and ethos	22
2.3. Peer support contexts and activities	25
2.4. Defining peer support: an impossibility?	27
3. Benefits and challenges	29
3.1. Benefits of peer support	29
Personal benefits	
Collective benefits	
Practical benefits	
Social benefits	
Benefits for peer workers	
Benefits for services and staff	
3.2. Challenges	32
Institutional challenges	
Psychological and emotional challenges	
Clash of values and ethos	
Resources and funding	
Professionalisation of peer support	
4. Training and support	35
4.1. Training	35
4.2. Support and supervision	39
4.3. Support to projects and groups	40
5. Good practice	41
5.1. Preserving the value base of peer support	41
5.2. A structure that supports organic development	42
5.3. Service users leading peer support	42

5.4. Preserving the variety and range	43
5.5. Providing support and resources	43
6. Preserving peer support: future work	45
6.1. Going beyond the mainstream	45
6.2. Valuing peer support in all its variety	46
6.3. Exploring the impact of professionalisation	47
6.4. Making a business case	48
6.5. Building social capital	49
References	50
Appendix 1: Online survey	52
Appendix 2: Points explored in interviews and visits	55

Foreword

The freedom to be, the chance to dream shows service-user leadership in action in mental health, taking up the challenge that if we are to improve people's mental health and wellbeing, we must all play our part.

In July 2012 the Government and its partners published *No health without mental health: an implementation framework*. That framework contains clear practical ideas about how organisations can make a reality of the mental health strategy, *No health without mental health*. We are currently drafting a companion document showing how service users, carers and the public can turn the ideals of the strategy into concrete actions. This report on user-led peer support in mental health and its findings around good practice demonstrates how service users can lead improvements in services and outcomes at an individual, group and service level. The benefits are particularly highlighted in user-led projects with marginalised groups, improving the quality of inclusion and outcome for service users from those groups.

I look forward to the continuing impact of service user leadership and peer support on the delivery of the six objectives of *No health without mental health*.



Paul Burstow, Minister for Care Services, August 2012

Acknowledgments

Alison and Jayasree would like to thank the following people and organisations for giving their views on peer support for this consultation.

- All the people who completed the survey
- Torsten Shaw (Making Waves)
- Raza Griffiths (SWAP)
- Steve Gillard (St George's, University of London)
- Karen Machin (Peer Support Network St Helen's)
- Premila Trivedi and the group members (Kindred Minds Theatre Company)
- Renuka Bhakta (Kindred Minds)
- Clare Ockwell (CAPITAL)
- Devon Marston, Coral Hines, Rima Williams, Paul Brewer (Canerows and Plaits)
- Joyce Kallevik and team (Wish)
- Helen Jones (MindOut)
- Tracey Orton (Roads to Recovery)
- Koula Serle (Re-energize)

We would also like to thank Elina Stamou and Anne Beales (Together), David Crepaz-Keay (Mental Health Foundation), and Patience Seebohm (independent researcher) for their input and advice on this project.

Our thanks also go to the networks and organisations who helped us disseminate the survey.

Summary of the Report

Peer support or mutual support has long been seen to take place wherever service users come together: on inpatient wards, day centres and drop-ins, in service user groups, and in the community. Recent developments in peer support, based on models developed in the US and aided by the promotion of a 'recovery-focussed' approach, have raised the profile of peer support in mental health and introduced the employment of peer support workers into mental health services. While there seems to be a general agreement that this is a welcome development, potentially leading to changes in organisational practices in mental health, there are also several concerns arising from the 'professionalisation' of peer support and how that might affect service user self-determination and mutual support.

Together commissioned this consultation in order to understand more about the different contexts in which peer support takes place and the influence of these new approaches on existing ones. Specifically, we were interested in what constitutes peer support, its values and ethos, the evidence for the need for service user-led peer to peer support and its benefits, and a sense of people's concerns and interests in the current context. This report presents the findings from this consultation and highlights areas for future enquiries, research and development.

Key consultation questions

- What is peer support? Who is a 'peer'? Are there differences in definitions based on diversity/diagnosis/experience or other factors?
- What evidence is there on the benefits of service user-led peer to peer support?
- How can we ensure that peer support develops in ways that makes it accessible to individuals or groups who are often excluded from progressive approaches in mental health?
- How do we address issues of inequalities in the way peer support is being developed, including: training, institutionalisation of peer support through mental health services, the impact of the professionalisation of peer support on user-led and community based peer support practices.

Consultation methods

1. We visited or interviewed nine peer support projects, eight of which were service user/carer led. Three were for service users from black and minority ethnic communities, one for service users from lesbian, gay, bisexual and transgender groups, one for women in prison and special hospitals and one for people with a first diagnosis of psychosis. Two of the projects were aimed at people in inpatient wards.
2. We undertook a survey using Survey Monkey to obtain views and perspectives about peer support more widely, which generated 44 responses representing

projects/initiatives set up specifically as peer support and others located within user-led and voluntary sector organisations.

3. The information collected was supplemented with reference to literature arising from predominantly service user and survivor sources.

What we learned:

What is Peer Support?

- Whilst a shared lived experience of mental distress is fundamental to peer support, it also needs to address other shared experiences, identities and backgrounds.
- Peer support has to be based on certain values and ethos, including empathy, trust, mutuality and reciprocity, equality, a non-judgemental attitude.
- Contexts and support that people describe as 'peer support' do not always fit neatly into definitions of 'intentional', 'formal', 'informal' or 'naturally occurring' peer support. This consultation did not attempt to define peer support: rather it has described it in a range of different contexts and communities.

Benefits and challenges

- The benefits of peer support identified here reflect many previous findings: personal benefits (such as confidence, self-esteem, empowerment, companionship), practical benefits (information, signposting), social benefits (social inclusion, challenging stigma and discrimination, challenging barriers specific to marginalised groups) and benefits for peer workers, staff and services.
- Some of the collective benefits (mutual understanding, shared identity, collective action) were particularly highlighted by the experience of user-led projects working with marginalised groups.
- The challenges of peer support also reflect previous findings. However, there were also some areas of difference. For example, the challenges of boundaries and role clarity tend to arise in relation to more formal approaches to peer support, while informal approaches seem to prefer peer support to develop organically with little formal boundary setting.
- Smaller voluntary sector groups and organisations offering informal peer support raised the professionalisation of peer support as a challenge to their ethos and survival.

Training and support

- The attention and resources given to training and support are closely related to the nature and context of peer support on offer. More focus is given to the needs for training and support where a more formal approach to peer support is on offer, and the role of peer support worker is distinguished.
- Few of the participants and only two of the projects had accessed formal training in peer support; many had accessed other related training such as listening skills, communication skills, group facilitation and WRAP training.

- Great value was placed on expertise by experience and the transferability of skills.
- It was thought vital to include some form of grounding in the history of the user movement, of user involvement and/or of a user-led values and ethos in peer support training.
- There was a general consensus that insufficient focus is given to diversity and equality issues in training. It may be that what is needed is ‘purposeful diversity’ training to address the different identities someone might come with. In many ways this issue is at the core of peer support.

Good practice

- **Preserving the value base:** Both the survey participants and the projects we interviewed underlined the need for peer support to be based in personal experiences and seeing peers as ‘experts by experience’. There also has to be the acceptance that this ‘experience’ is diverse and different and peer support work must find ways to deliver on this diversity and difference.
- **A structure that supports organic development:** Boundaries can be valuable in ensuring that everyone involved can work in a safe environment; but they need to allow for the natural, organic growth of the peer relationship and for informal approaches to peer support to flourish.
- **Service users leading peer support:** One of the fundamental principles of peer support is that it is user-led; losing this was something that people were concerned about.
- **Preserving the variety and range of peer support:** Good practice in promoting peer support will ensure that the wide variety of approaches is preserved; indeed, several projects are delivering peer support in more than one way in order to ensure to meet the diverse needs of the people they work with.
- **Providing good support and resources:** Supporting peer supporters in their work is an important element of good practice. Examples included external peer supervision, opportunities to talk to other peer supporters, issue-based training in looking after oneself, listening skills and working with differences and diversity.

Preserving peer support: future work

- **Preserving the history:** Peer support covers a range of different contexts, activities and ways of working. The history and development of peer support encompasses self-help groups, mutual support groups, the user/survivor movement, the growth of survivor activism, self-management, and what is often referred to as ‘intentional’ peer support.
- **Understanding the gaps:** To date, this range of literature has not been brought together in any one place and there remain some significant gaps in our understanding. There are also significant issues of tension and dissent which may be in danger of widening the gaps.
- **Going beyond the mainstream:** Peer support encompasses the recognition of a range of shared identities, experiences and backgrounds. There is a

need for a more sophisticated understanding of the nature of peer support where it concerns people with experiences of marginalisation.

- **Valuing peer support in all its variety:** There is a great diversity within peer support groups and activities and it is important that equal attention is paid to how these contribute to the wellbeing of people who have mental health needs. There needs to be more investment in exploring peer support in all its forms and supporting community based peer support initiatives with more funding and resources.
- **Exploring the impact of professionalisation:** Our consultation shows that there are concerns about how professionalising peer support will affect community based, organically evolving and issue-focused peer support. There needs to be more exploration into this given that community support structures are already affected by cuts in public spending.
- **Making a business case for peer support:** There is considerable consensus about the benefits of peer support in its many different forms. Its 'effectiveness', however, is more difficult to prove, as the benefits of peer support are felt more at an individual, 'lived' level, not necessarily quantifiable in health economic terms. There is more work to be done to consolidate the evidence for the effectiveness and benefits of peer support as it occurs in informal, mutual, self-help and peer support groups.

1. Introduction

Peer support or mutual support has long been seen to take place wherever service users come together: on inpatient wards, day centres and drop-ins, in service user groups, and in the community. Recent developments in peer support, based on models developed in the US and aided by the promotion of a ‘recovery-focussed’ approach, have raised the profile of peer support in mental health and introduced the employment of peer support workers into mental health services. While there seems to be a general agreement that this is a welcome development, potentially leading to changes in organisational practices in mental health, there are also several concerns arising from the ‘professionalisation’ of peer support and how that might affect service user self-determination and mutual support.

In undertaking this consultation, we were influenced by needing to understand more about the different contexts in which peer support takes place and the influence of these new approaches on existing ones. Specifically, we were interested in what constitutes peer support, its values and ethos, the evidence for the need for service user-led peer to peer support and its benefits, and a sense of people’s concerns and interests in the current context. This report presents the findings from this consultation and highlights areas for future enquiries, research and development.

1.1 Key consultation questions

The consultation focused on the following key questions:

- What is peer support? Who is a ‘peer’? Are there differences in definitions based on diversity/diagnosis/experience or other factors?
- What evidence is there on the benefits of service user-led peer to peer support?
- How can we ensure that peer support develops in ways that makes it accessible to individuals or groups who are often excluded from progressive approaches in mental health?
- How do we address issues of inequalities in the way peer support is being developed, including:
 - Training
 - Institutionalisation of peer support through mental health services
 - Impact of the professionalisation of peer support on user-led and community based peer support practices

1.2 How the work was done

The consultation questions were developed based on the project brief from Together and a reading of existing literature on peer support. We found that existing literature seldom addressed or discussed the contexts of peer support and mutual help within marginalised communities. We were especially interested in peer support work that

was going on within settings addressing the issues of marginalisation, within specific mental health settings and within contexts addressing specific needs.

In order to capture a wider sample of views, we conducted a quick survey exploring definitions of peer support, what it constitutes in everyday practice and views of people involved in giving and receiving peer support. The survey was disseminated through various networks and organisations, including user-led organisations, national charities and other user/survivor forums.

Telephone interviews and visits to explore specific contexts were conducted with teams or representatives of organisations/projects¹ working with black and minority ethnic communities, women in prisons, people with a specific mental health need, and lesbian, gay, bisexual and transgender (LGBT) communities, along with those working with all communities.

In addition, we also spoke with four service user/survivor trainers engaged in delivering training on peer support.

Limitations of the study

This was a small consultation with an emphasis on finding out more about peer support within user-led and marginalised communities. We set out to gather some views about peer support from people involved in it in different capacities. The methodology used – individual interviews, visits to projects and an online survey – was chosen to help elicit as wide a range of views as possible within the time and resources allocated for the project. As such, the conclusions drawn from the data collected need to be read as descriptive rather than prescriptive or exclusive.

The report mentions some specific training programmes and peer support initiatives. These are based on the views expressed by some (but by no means all) people involved in these projects. Our purpose was not to evaluate these projects or initiatives but to present these views. Wherever possible, we have referred to evaluation reports and other relevant materials available at the time of writing.

The information in this report provides a wide picture of the current debates and thinking about peer support, which we hope will be useful for anyone interested in learning about and developing peer support. At the end of the report, we also point to some questions that require further in-depth investigations and research.

1.3 The survey

The survey was set up on Survey Monkey and ran for four weeks. We received a total of 44 responses to the survey. The demographic diversity of those who responded is given in the table below.

¹ Peer support explored through telephone interviews/visits varied widely in that some were organisations while others were projects or initiatives within organisations. For ease of reference, we will call them 'projects' in this report.

Table 1: Demography of survey respondents		
	Number	Percentage
Age		
26-35	4	9%
36-45	8	18%
46-55	18	41%
56-65	7	16%
65+	1	2%
No response	6	14%
Gender		
Women	30	68%
Men	10	23%
No response	4	9%
Ethnicity		
White British	22	50%
BME	14	32%
Other ethnicity	1	
No response	7	
Sexual orientation		
LGB	4	9%
Heterosexual	25	57%
No response	15	34%
Disability		
Long term health condition or disability	30	68%
No health condition or disability	9	20%
No response	5	
Religion		
Christian	14	32%
No religion	12	27%
Other religion	6	14%
No response	10	23%
Spiritual	2	5%
User/Carer		
Mental health service user	19	43%
Former mental health service user	11	25%
Carer	5	11%
No response	9	20%

Context and nature of peer support

Fifty two per cent of the respondents said that they attended a peer support group or service for mental health service users and/or carers. Seventy five per cent of the respondents said that they offered peer support to others. Forty five per cent of respondents said that they received and offered peer support through the groups they attended.

Of those respondents who said that they attended a peer support group or service through which they received peer support, 59 per cent said that this was in the form of mutual support while 15 per cent said peer support was offered by paid workers. Three people said that they had both mutual support and paid peer supporters.

Of those who said they offered peer support, 39 per cent were paid workers and 33 per cent worked in a voluntary capacity. A further 27 per cent said that they offered peer support as a group member.

Those who offered peer support were asked to specify what kind of context they worked in as peer supporters. All those who said that they offered peer support as part of a group said that they did this in informal contexts, through self-help, support groups etc. Those who worked as paid peer supporters were more likely to be delivering peer support within formal structures, with a clear distinction between peer workers and those they support. The following table lays out the context of peer support.

	All	Paid peer supporters	Volunteers	Group members who consider themselves peer supporters
Formal, with a clear distinction between peer workers and those they support	15%	38%	0%	0%
Formal, with people supporting each other	9%	15%	9%	0%
Informal (self-help, support groups etc.)	58%	15%	55%	100%
Both formal and informal	12%	23%	27%	
Don't know	6%	8%	9%	

Description of peer support groups

The survey asked the respondents to describe the peer support groups and activities that they were involved in. Based on this, some groups clearly identified themselves and their work as peer support while some others considered their work peer support even though they did not call them that. There were projects/initiatives set up specifically as peer support while others were located within user-led and other voluntary sector organisations. The following table sets out the nature of groups and activities.

Peer support groups	
Description	Access
1. 'Graduates in psychotherapy'. 7 members. 1-to-1 and group.	For people leaving therapy

	“Many of us had learnt skills through our Systemic Group Psychotherapy and wanted to be able to continue using these in our day to day life and to support each other in our lives.” (Set up at the request of NHS psychotherapist)	
2.	PS group in Hampshire. Drop-in and 1-to-1 in the community.	For people who have a mental health support worker or care coordinator in Fareham and Gosport areas
3.	STUFF (Stockport). Hospital-based drop-in weekly. Information sharing, training in mental health, volunteer training, promoting UI in policy/research	For service user/ex-service users over 16
4.	Pub social group run by peer supporter	For everyone
5.	‘Informal’ peer-run service (until recently called ShUSH – service user self-help). Have lots of peer and self-help groups and about to start education programme.	Have specific groups like Epilepsy, women, ‘Adult Parents Together’ and also daily social group open to all
6.	Specialist – safeguarding vulnerable individuals	Open to professionals working in the clinical area of mental health
7.	Parents and carers of people with learning disabilities and dual diagnosis. Practical services including holiday and weekend schemes. “The group covers a wide area of North London and membership reflects the diversity of those communities.”	For all parents and have a broad definition of learning disability and mental health. Several members have adult children who are using forensic mental health services
8.	PS for mental health service users with an out of hours service included	For everyone
9.	‘Intentional’ PS. Regular meetings, community project	For disadvantaged isolated adults from all walks of life
Voluntary sector groups		
	Description	Access
1.	Reading Your Way MH Day Centre (part of Together). Day centre and drop-in. Not called PS; not user-led	For mental health service users
2.	‘Gardening for Health’ (not specifically PS or user-led)	For anyone interested in gardening
3.	Local Mind-run groups on advocacy, user forums etc.	For everyone, formal association with mental health services is not necessary
4.	Afiya BME Carers Panel. Educate professionals, inform carers, Buddhist Carers Group, relaxation, weekend breaks	For BME carers
User-led groups not specifically called PS		
	Description	Access
1.	Group run by Mind. “An informal drop-in where we have naturally formed peer support.”	For everyone
2.	User-led drop-in space	For everyone; there is a group specifically for those with drugs and alcohol issues
3.	Southwark Mind women’s group and parents group both facilitated by users	Women’s group for all women and parents’ group for all parents. Have a good mix of ethnicity and class
4.	CoolTan Arts (art classes, cultural/social events, self-advocacy, facilitated both by users and non-users)	For everyone. Have a good mix of ethnicity and class
5.	Speak Out Against Psychiatry (protest group also functions as support group)	For those who believe psychiatry does more harm than good
6.	‘Listening for Change’: “We listen to each other and then come together as a group to find a solution to whatever is our biggest barrier.”	For parents of disabled children, run through the charity Parents for Inclusion
7.	“Use theatre and discussion to help service users reflect on what they want and how to get it.”	For everyone
8.	User-led Forum (service user voice in local mental health service provision)	For everyone
9.	‘Implementation Group’ working on policy implementation in Camden and Islington MH Trust	For everyone although you have to be nominated or voted in to join
10.	Group that meets monthly – arranges training and support groups, outings	For people with specific diagnosis
11.	BME user-led group. Self-advocacy, self-development, campaigning	For BME service users

The above table shows that, in the community, a wide range of activities and types of services/groups are understood as peer support, including self-help, 'informal' peer support, 'intentional' peer support, campaigning, involvement activities, support groups, creative/education activities.

1.4 Telephone interviews/visits

We interviewed or visited a total of nine projects or groups offering peer support (see Table 4). Two of these, Kindred Minds and Kindred Minds Theatre Company (KTC), are closely connected in that KTC evolved out of Kindred Minds. All can be loosely described as peer support projects. However, one organisation, Roads to Recovery, is managed by someone without direct experience of mental distress and another is a project that is based within a voluntary sector organisation, MindOut, which is not a mental health user-led organisation. Five of the nine projects have paid peer workers. The other four are group-based with an approach that regards all members as equals; one of these has a facilitator paid on a freelance basis.

In addition to the visits and interviews, we have acquired and examined the evaluation reports on two of the projects: CAPITAL's report to the commissioners and an evaluation of the first year of Canerows and Plaits.

Table 4: Peer support projects interviewed or visited

		Organisation	Who is it for? Aims	Peer support	Funding
1	Canerows & Plaits	Based within Sound Minds – user-led organisation	BME people on inpatient wards in Wandsworth (although now working with everyone); arose out of concern for BME service users on wards not receiving the care they need	Ward visiting – one to one Peer workers working voluntarily for the first four weeks; paid after that	Funded for 3 years by Comic Relief
2	CAPITAL	Service user led organisation working across West Sussex; meet monthly in three localities plus additional local activities.	People in inpatient wards – to help people recover from crisis	Mix of individual and group – groups are a way of getting to know people and letting them know that individual support is available. Paid peer workers	Local PCT funding for another year – not sure what will happen then. £97,000 for first year; probably less for 2nd
3	Kindred Minds	Project within Southwark Mind which is a ULO focusing on campaigns, policy work and user-led services.	BME service users. Evolved out of the need for Southwark Mind to better meet the needs of BME communities	Personal development: focuses on reclaiming power, self-esteem, having a voice; Crossing Cultures: Learning about each other. Focuses on understanding culture, diversity, history, heritage etc.; Gaining Ground: Focusing on user involvement, building a collective voice of BME service users locally	Big Lottery
4	Kindred Minds Theatre Company (KTC)	Emerged out of Kindred Minds – group came together to write and perform a play	Black mental health service users – evolved out of the interests of a group attending Kindred Minds	Mutual support group based on shared experiences beyond mental health, expressed through creative activities. No paid workers	Funding from Kindred Minds for theatre workshops, facilitation and out-of-pocket expenses for members; currently facilitated by a service user paid on a freelance basis
5	MindOut	Mental health service run by and for lesbians, gay men, bisexual and trans people based in Brighton and Hove.	Open to all LGBT people with any mental health issues – from mild to severely disabling.	Group based: open groups and closed groups and special groups; with individual support available as back-up. Paid group workers + manager	Funded as part of the whole Mind Out service, currently Big Lottery
6	Peer Support Network, St Helen's	No organisational base	Open to anyone who has been a long term mh service user. Have a core group of 6, larger membership of 20.	Mutual group ; informal but based on a 'mutual agreement' to focus on strengths, positives, solutions. One member at a time has mobile phone to take calls from members needing support within specified times. No paid workers	£1000 to set up. No funding currently
7	Re-energize	Oxford based mental health user-led sports and social group run by volunteers.	Mental health service users; welcome people who have made a step towards 'clinical' recovery. Help and support to achieve a healthier lifestyle; a key aim is to combat stigma and to aid people's participate in the community	Informal, user-led model based on group activities: sports and social. Run by volunteers, mutual peer support for all group members. All members equal. No paid workers	Had government funding as a start up grant. Then funded by direct payments. + ongoing funding from the Oxfordshire Service User-led grant fund (Joint Oxfordshire Council and primary Care Trust fund). + some funding from Monument Community Trust in Oxfordshire. Currently negotiating with

					PCT,
8	Roads to Recovery	Small user/carer-led charity in Nottingham; one manager + 2 peer support workers.	People with psychosis, aged 18 -35 (not strict about the upper limit)	Formal, structured, mainly group work but some one to one work; Code of conduct for Peer Support Workers, strong emphasis on support and personal development. Paid peer workers	Core funding from Nott City NHS; have now teamed up with LHA Azra and successful in getting core funding for future. Estimates it costs £3-4,000 per month in all.
9	Wish	User-led charity working with women with mental health needs in prison, hospital and the community.	Women in prisons and special hospitals; women leaving those institutions. 'vulnerable' women. Role modelling is part of it, to see what is possible.	Employed peer workers meet women in prison, mainly one to one ; also on coming out. Helping women to access opportunities.	City Bridge; Comic Relief

Organisational base

Several of the peer support projects are based within user-led organisations: CAPITAL inpatient peer support service (in CAPITAL Project Trust); Canerows and Plaits (in Sound Minds), Kindred Minds and KTC (in Southwark Mind). Re-energize and Roads to Recovery are organisations set up specifically as peer support organisations. Peer Support Network St Helens is a self-organised group that exists without an organisational base. The MindOut peer support service is based within the voluntary sector organisation, MindOut, which is not mental health service user-led but is LGBT-led: a service run by and for LGBT people. Wish is a user-led organisation offering a range of services to women with mental health needs in prisons, hospitals and in the community.

Funding

Information was not available on all of the projects about the amount of funding involved but sources of funding were given. From the information we have, funding sources and amounts were immensely varied – from no funding to around £97,000 per annum. Equally, rates of pay for peer workers vary a great deal. Those employed within statutory services may be on Health Care Assistant rates: £12-13,000; in Nottingham they are on Band 3 - £14-15,000. In the voluntary sector, where most of our information comes from, peer workers may be paid around £8.50 per hour (CAPITAL).

Peer Support Network St Helens receives no funding, while KTC is facilitated by a freelance service user. At the other end of the spectrum, CAPITAL received £97,000 for its first year from the local PCT, albeit for a large-scale project employing 8 posts plus 6 relief staff being paid, supported and supervised across a large geographical area. Several projects had received funding from NHS Trust or PCT sources, and one was initially funded through the collective use of direct payments. Outside of statutory funding sources, the biggest funders appeared to be Comic Relief and the Big Lottery. MindOut (funded by the Big Lottery) provides the peer support service as a part of that overall funding.

Membership

One of the aims of our work was to look at how peer support worked within specific communities and/or addressed issues of diversity, equality and marginalisation (see Table 4). Hence, some of the projects we chose are specifically intended for a particular group of service users (BME; LGBT; women in or leaving prison) whereas others are intended for people at a particular point in their journey (inpatient/crisis; people at an early stage of psychosis). The implications of these contexts are discussed later in relation to shared identity.

Both Canerows and Plaits and CAPITAL offer peer support to people on inpatient wards, so at a point of crisis in their lives. Re-energize focuses explicitly on people in the community and encourages people to join who are already some way along the road towards recovery. MindOut, although exclusively for lesbians, gay men,

bisexual and transgender people, is open to people with any kind or severity of mental health problem. Peer Support Network St Helens is similarly open to people with any mental health problem and does not specifically require people to have used mental health services or received a diagnosis.

Activities

KTC members come together through creative activities while Re-energize is engaged in sports and social activities. As well as group meetings, members of Peer Support Network St Helens take it in turns to take responsibility for a mobile phone to take calls during specified times from other members who need support.

MindOut's groups are formal and structured: one is open access and one is a closed group, with additional groups developing in response to demand from service users. A particularly successful one has been the Suicide Prevention group, which enables people to engage with difficult issues from the outset due to its subject matter.

The ward visitors at Canerows and Plaits aim to engage people in conversation on a one-to-one basis, sometimes enabling them to engage in other activities. The CAPITAL peer workers offer group activities, as a way of getting to know people and engage in one-to-one support. In one locality, they offer what they call a "light touch" recovery group; others include arts and music. Roads to Recovery peer workers will meet people individually in the community, go for coffee or meet where the service user wants to meet; they might talk about common interests or engage in deeper issues according to the needs of the service user. They have also developed a successful music production group in conjunction with a local music organisation.

Wish offers peer support with the peer supporter meeting the women when they are in prison to build up a relationship, then meet them as they leave and engage them in regular visits to Wish, with a view to helping them to plan and think about educational and vocational opportunities.

2. Peer support: what does it mean?

Literature reviews on peer support show that there are several definitions of peer support and ways in which different types of work are categorised as ‘intentional peer support’, ‘informal peer support’ etc. While doing this work, we refrained from defining peer support. Instead, we asked the participants to tell us how they defined/described the work they do and what criteria they thought important in seeing someone as their ‘peer’ in this context. As we have seen in the previous section, the projects we consulted with and the respondents to the survey described a wide range of scenarios and activities as ‘peer support’. The main themes arising from these discussions are:

- Whilst shared lived experience of mental distress is fundamental to peer support, it also needs to involve other shared experiences, identities and backgrounds
- Peer support has to be based on certain values and ethos, including empathy, trust, mutuality and reciprocity, equality, a non-judgemental attitude
- Contexts and support that people describe as ‘peer support’ do not always fit neatly into definitions of ‘intentional’, ‘formal’, ‘informal’ or ‘natural’ peer support

These themes are discussed in detail below.

2.1 Who is a ‘peer’?

The term ‘peer support’ generally refers to “mutual support provided by people with similar life experiences as they move through difficult situations” (Repper and Carter 2010). In the context of peer support in mental health, the fundamental ‘similar life experience’ is a shared personal experience of mental distress. But beyond this, the idea of ‘who is a peer’ has not been examined at any length in peer support literature. Inquiries from specific contexts (for example, from the points of view of racialised communities) into service user involvement (Blakey 2005, Kalathil 2011a) and into the meaning of recovery (Trivedi 2010, Kalathil 2011b) have shown that a shared experience or context of mental distress is often not enough to address the specific needs and concerns arising from experiences of marginalisation. Given this situation, we decided to ask people their views on how they defined who a peer is.

Different people emphasise different aspects when asked to describe who they would consider a ‘peer’. For 75 per cent of the respondents to our survey, a peer needed to have more than a shared personal experience of mental distress in common with them. Of these respondents, 76 per cent said that shared ideas about what recovery

means would be valuable in a peer, including a belief in self-management and the idea of being an 'expert by experience'.

“A lived personal experience of mental distress either as an individual, a relative or a carer of someone who suffers. This person should be active in their own self-management and have a clear notion of themselves as being an expert by experience.”

“A person who has experience of mental distress and is an expert by experience.”

Shared understandings of specific diagnoses and their effects were important for 73 per cent of respondents while shared views about medication and other treatments were important for 58 per cent of respondents.

“Shared feelings when treatments were not correct and may have made matters worse. Then to receive ... care from one human being to another.”

“Shared understanding of the harm that psychiatry does.”

For many of the respondents to our survey, a peer is someone who has specific experiences of using mental health services similar to theirs.

“A peer is a survivor of mental health services, especially of being an inpatient.”

“A person who has survived the mental health system. Preferably somebody who has been sectioned under the MHA but certainly a person who has experienced inpatient care...”

The views about who a peer is were reflected in the range of support and activities offered by the projects we spoke to. Some projects did not pre-define what 'mental distress' is or insist on their members or peer supporters having received a diagnosis or used mental health secondary care services. Indeed, for projects like Wish, it would be difficult to impose any definitions of what constitutes 'experience of mental distress' as mental health problems remain a largely hidden but heavily contributing factor to women's vulnerabilities.²

More than half (55%) of the respondents to the survey said that peers would be people who shared gender, ethnic background, sexual orientation, age groups, faith etc. Among respondents from black and minority ethnic communities, 66 per cent felt that a shared ethnic and cultural background would be important in a peer.

“Someone who has similarities to the person in need of support, e.g., age, gender, ethnic background, and understanding of the issues around mental health.”

² According to data we received from Wish, 78 per cent of women in prisons had 'diagnosable mental health problems' compared to 15 per cent of women in general population (data compiled from Prison Reform Trust Factfile, 2010; Women Prisoners, 2008; The Corston Report, 2007).

“Somebody that shares the same experience as you, also around your cultural practices as well as religious needs.”

Respondents spoke not just about shared backgrounds but also the understanding of the kind of barriers that marginalisation can create.

“...Shared life experiences of oppression, i.e., racism and its impacts on life... Differences important too to enable new thinking, learning and growth.”

“Also shared experiences of barriers that affect you and your family needs.”

The importance of shared backgrounds and experiences that go beyond a shared experience of mental distress was stressed also by many of the projects we spoke to. Of the nine projects, six were offering support to specific marginalised groups, including service users from racialised communities, from LGBT communities, women in prisons and people with a first experience of psychosis. All these projects considered elements of shared identities and experiences beyond that of mental distress central to their concept of peer support.

For members of KTC, the specific experience of being black survivors of the mental health system was a vital part of their sense of belonging and supporting each other – sometimes more important than the shared experience of mental distress and the psychiatric system:

“We can relate to each other. I can talk to you as a black person and you’ll understand what I mean.”

Similarly, for Canerows and Plaits, the fact that their ward visitors could understand and relate to the cultural backgrounds of the people they were visiting in the wards was crucial in the ‘give-receive’ relationship that they cultivated:

“You can only understand who you are, what you are and what is happening to you only if you see the experience from the context of your own culture.”

The MindOut manager also spoke of the importance of members being lesbian, gay, bisexual and transgender together:

“It is absolutely why they come here. A lot of people have had very poor experiences of other mental health services. In other mental health services, there is no guarantee that people will not be homophobic or that the service provider will do anything about it if they are. Sometimes it is the less obvious heterosexism that is more of a problem. People don’t want to go through all that, particularly when in distress.”

She talked about the silence surrounding LGBT mental health issues, the discrimination people can experience from both LGBT and mental health

communities because of their ‘otherness’ and the need for a safe space that this leads to.

The peer project worker at Wish who works with women in prisons also emphasised the need for shared experiences and identities, in this case of having been in prison:

“Women often say ‘oh you don’t know what it is like’ and me saying ‘actually I do know’ makes them open up and trust me in a different way from trusting non-peers.”

An issue that we were not able to explore in the research, but which has a significant impact on the experience and delivery of peer support, is geographical location. For people living in rural areas, isolation can add to the difficulty of finding and benefitting from peer support and, consequently, the way in which people access or deliver peer support may necessarily be very different. This may be a situation in which ‘virtual’ methods will work better. The need to address stigma and discrimination as part of peer support may also be more significant in smaller, close-knit communities, where people who wish for confidentiality and anonymity may look for support away from their immediate neighbourhoods.³

2.2 Values and ethos

Mead (2003) defines peer support as “a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful.” Although not all examples of peer support that we came across in this consultation were based on an explicit ‘mutual agreement’, respect and shared responsibility were seen as key values. Other ‘qualities’ that came up often included empathy, a non-judgemental attitude, equality, confidentiality, trust, openness and the willingness to be supportive and helpful and also to receive support (mutuality).

“Someone who has had the same or similar experience that I have had, and empathises with me. The person can encourage me and receive encouragement from me too. We share aspirations and have shared visions.”

“Someone who listens with respect (and interest); who can be both objective but also offer concern and if necessary compassion, someone who is willing to look at options, possible actions and if possible someone who has experience of the journey you are making. This experience can be through support of a friend, family member or as a direct user.”

“Ability to be trusted, confided in, loyal, committed and believe unequivocally, maybe, in the person they try to help.”

The values addressed here could all be part of an enabling relationship with a friend. So how does peer support differ from a friendship? Indeed, for some groups we spoke to, there was a blurring of distinction between the two. Both KTC and Re-energize talked about the formation of natural friendships through groups. Some

³ There is no consensus on this issue, but for a recent report highlighting this issue in terms of how people access services see Pacitti, R et.al. (2011).

members of KTC hesitate to use the term 'peer support' while others see it as important to group identity: "We have come here because of what we share." The environment of mutual support that happens within the group is providing a context for enduring friendships to form. This is very similar to the ethos described by Re-energize too.

For some people, a peer is distinguished from a friend by having that 'extra something' that enables them to be able to offer support in an objective way. For CAPITAL, for example, a peer is 'an informed friend' who comes alongside you:

"You have to be prepared to share more of yourself, what works for you although not in a didactic way."

Similarly, for Kindred Minds:

"A peer is someone who has had their own experience that resonated with mine and so we can support each other in a way that is personally useful... Someone who can help me think through what is happening to me rather than tell me what is happening to me based on their experience."

These quotations also illustrate the importance of a peer being able to stand back a bit from their own experience, in order to enable someone to find their own solutions, rather than telling someone what to do based on their experience of what works for them.

Another key theme to emerge is the principle of equality and mutual support. For example, an underlying ethos of equality and reciprocity unites projects like KTC, Re-energize and the Peer Support Network St Helens. Although KTC does not call itself a peer support group, mutual support is one of the key reasons why they come together:

"I'm holding her up when she's going down and this other person is holding me up. That's what peer support is all about."

Canerows and Plaits also emphasised that peer support is a two-way process; it is about giving as well as receiving. For one of their peer supporters who work as a ward visitor, it is an on-going learning path:

"People say it is 'rewarding' but the idea of receiving is much more than that. It's like I am only now beginning to understand what mental health problems are, including my own experience, what I have been through myself. As a patient on the ward, you understood that experience in a certain way, but as a person going back as a peer supporter you get a different understanding of it. When one says we use our experience in peer support, we are not necessarily using our experience of having been an in-patient, but this understanding of mental health issues that is always developing and changing."

Wish spoke of the prevailing view that women who are in prisons or with mental health needs are always on the receiving end of 'help'. Peer support is a way of

valuing what skills and experiences they might have and making it possible to share these with others, thus experiencing the meaning of full citizenship.

For Peer Support Network St Helens, this reciprocity is reflected in practical, everyday terms as well. The focus is on the positive aspects of people's lives and supporting people to find their strengths and doing simple things to change their lives. This is reflected in the activities that they do together, for example, supporting a member in managing her finances through help with budgeting and shopping or offering paired-up help for someone to decorate their flat in return of similar services when others need it.

A further key theme that emerged is shifting the patterns of 'care' within mental health services by focusing on hope and optimism. For example, Peer Support Network St Helens has a 'mutual agreement' that ensures that members keep a focus on supporting each other through identifying strengths and seeking solutions to any issues, and sees this as a means of distinguishing the network from other forums engaged in actively working to change mental health services or social groups where people come together for social and leisure activities.

Some of the projects (particularly projects where there was a clearer distinction between the peer supporter and those they supported) saw the idea of a 'role model' as a means of focusing on hope and optimism. So, for Roads to Recovery, it is important that the peer workers have personal experience of psychosis. For Wish, the peer workers are acting as role models for the women in prison, enabling them to see that it is possible to have a job and a life; that these things are not out of their reach. Similar views were given about the two services offering peer support to people on inpatient wards (CAPITAL and Canerows and Plaits), suggesting that one element of role modelling is to introduce the idea – and the hope – that there are possibilities and options beyond people's current situation. It was seen as particularly powerful for service users to be able to see people 'like them', whether as black service users, people who have had specific experiences of mental distress such as psychosis or as women with the experience of being in prison, in valued roles providing support to others.

The view that peer support needs to be based in locations where service users had full control and influence over policy and practice was also expressed strongly. User-led organisations were seen as the ideal locations for peer support.

“Peer support does not have to function solely within a formal service model. In user-led projects with 100% user involvement, peer support can work within a shared community of common interest and endeavour.”

As we have seen, eight of the nine projects we spoke to were user-led (or user and carer-led as in the case of Roads to Recovery) projects and/or projects based within user-led organisations. All of them emphasised the need for initiatives and pieces of work that they took on to be led by their members and arising from their interests and needs. 'Organisational take-over' was a key concern when peer support was placed

within professional or non-user-led organisations (see section discussing ‘Good Practice’ for more details).

2.3 Peer support contexts and activities

We have seen that there is a wide range of activities, projects and ways of working that are described as peer support (See chapter 1). It would seem that the existence of shared life experiences, identities and backgrounds as well as the values and ethos described above are the criteria that people used in calling what they do peer support. Within this, people took on several roles, paid, voluntary or mutual, and offered a range of support and activities, both in groups and one-to-one.

The survey showed that paid peer supporters worked alongside professionals, doing similar activities and jobs like facilitating groups, recovery planning, day activities and attending meetings.

“[The organisation] works on the premise that the day centre is service user-led with the peer supporters on hand to support and assist the members in becoming more responsible and to make decisions for themselves about what they want from the centre. We enable this by having open weekly meetings, the notice board, peer support staff meetings, and bimonthly committee meetings...”

In some instances, the activities that the peer supporter was involved in were clearly defined, sometimes as distinct from that of the professionals.

“Inpatient services and developing a community project running recovery workshops. Being very clear about our distinctiveness from other professionals.”

Other paid peer supporters worked in a more informal way, providing support and advice as necessary, ‘being there’, listening to people’s concerns and finding ways to overcome them etc.

“[I work] within a mental health trust since 2003. Talk to people, share, role model of hope/recovery.”

“Drop-in where the centre is open for users to come and relax and socialise knowing that there are people there to help if needed.”

“I meet people in the community on a one-to-one basis such as in cafes.”

Volunteer peer supporters also offered a range of support and services, facilitating groups, organising activities, and running social spaces.

“I ... offer a drop-in, research opportunities, training, information and guidance.”

“I facilitate a peer group and co-ordinate our project. In our project, we provide many activities, i.e., art, woodwork, drama, IT skills, confidence

courses, cooking etc. We have formed a co-operative and run this ourselves.”

They also offered one-to-one support to people, working through issues face-to-face, doing ‘check-ins’ and providing personal support.

“I used to offer out of hours support by text message. Some people find it easier to receive support like that.”

“I am retired but spent 40 years as a medical secretary and paralegal in medical negligence. I help patients decipher their medical notes and clarify their rights under the MHA. If asked, I will act as an advocate... The staff are agreeable to my taking on such cases.”

By and large, volunteer peer supporters worked in informal peer support spaces, although one person worked in an organisation that had both formal and informal peer support services.

All respondents who said that they offered peer support as part of the groups they belong to said they did this in an informal way. Activity groups, sharing information and signposting people to specific services and support they need, arranging training opportunities and one to one support through sharing experiences and helping people work out their own issues featured prominently.

“I help share information and links. Try and make others not feel ‘stuck’ and instead more empowered and able to act...”

“Providing a listening ear, information, signpost to other agencies...”

“Facilitate mental health service users to become trainers, facilitate activity groups as part of the BME user-led organisation.”

The nine projects we interviewed/visited also demonstrate a wide range of approaches to peer support. Peer Support Network St Helens specifically named itself to make their primary purpose, peer support, clear and has a formal ‘mutual agreement’ for group members, while Re-energize, Kindred Minds and KTC work from an ethos of peer support without calling themselves peer support projects. An important principle for these groups is that they operate on a fully mutual and equal basis without power relationships, although some people may take on volunteer/facilitator roles within the group.

Some projects predominantly use a one-to-one approach and others operate through groups alone, with several providing a combination of both. Roads to Recovery, for example, operates predominantly through one-to-one relationships; however they do have a couple of group activities through which service users can meet each other and the other peer workers.

CAPITAL in its everyday activities as a user group working across West Sussex, operates through group meetings and values the mutual support and equality of its

members. It is only the inpatient project that takes on the distinct model of peer support that operates on a more formal basis with peer workers offering peer support to service users.

MindOut offers peer support mainly through a series of groups facilitated by group workers; however these are backed up by individual support offered by the workers to the members. Often new members start with individual support before joining a group. In addition, informal peer support takes place in and around the service through a range of social and other activities.

2.4 Defining peer support: an impossibility?

Examining the literature on peer support, it is clear that many people allow for the wide variety of views on what constitutes peer support and resist an exclusive definition. However, there also seems to be a trend, following on the developments in appointing peer workers within statutory organisations, that defines 'intentional peer support' as something unique and different from many of the descriptions of activities and ethos discussed above. For example, Davidson et al (2006) defines peer support thus:

“We conceptualize peer support, in contrast, as involving 1 or more persons who have a history of mental illness and who have experienced significant improvements in their psychiatric condition offering services and/or supports to other people with serious mental illness who are considered to be not as far along in their own recovery process.”

They arrive at this definition by differentiating 'peer support' from mutual support and from user-led programmes and activities which may also be providing mutual support and self-help.

In Bradstreet's (2006) typology of peer support 'formal/intentional' peer support is defined as "use of consumers/service users as paid providers of services." There seems to be an emerging consensus that 'intentional peer support' is the employment of service users to provide support to their peers (Repper and Carter 2010). However, this definition can be misleading because, as we have seen, 'intentional' peer support can happen within the community, in both formal and informal ways and in group and one-to-one situations. For example, Peer Support Network St Helens was set up 'intentionally' as a peer support group but functions without an organisational base, in a voluntary capacity. KTC came together 'intentionally' to explore and represent black survivor experiences and has developed 'informally' into a mutual support group. The 'intentional' peer support provided by Canerows and Plaits functions in 'informal' ways within ward situations but without assigning specific people to peer supporters.

The definitions we work with are not just a matter of academic clarity; they are tied up with funding decisions and policy priorities. The imposed distinctions between what is defined as peer support and support through other self-organising groups "conceal the fact that both types of groups are characterised by mutual aid and reciprocity, but

it may cause the groups to be perceived differently” (Seebohm, Munn-Giddings and Brewer 2010). It may also result in some activities and groups getting funded while others are left behind.

3. Benefits and Challenges

There are strong similarities between our findings and findings from the literature, particularly in relation to the personal benefits of peer support. Some of the challenges are rather more variable, depending on the nature and context of the peer support involved.

The literature on peer support has highlighted a number of benefits for peer supporters and for those they support, mutual benefits for group members and for staff and services where they are employed as part of the service. For example, Repper and Carter (2010) identifies that employing peer support workers can result in many benefits including a reduction in admission rates and increased community tenure, empowerment, social support and social functioning, empathy and acceptance, reducing stigma and engendering hope. They also identified that peer support can benefit peer workers by aiding their continuing recovery.

Similar benefits were identified by Faulkner and Bassett (2010) who consulted with five service user/peer support groups. This study found that peer support resulted in benefits such as shared identity, self-confidence, helping others, developing and sharing skills, mental wellbeing, access to information and challenging stigma and discrimination.

The literature has also identified the challenges of peer support. For Repper and Carter (2010), these are mainly associated with the challenges facing the peer worker within mental health services: understanding the boundaries between friend and worker, power differentials, stress for peer workers, accountability, training and ongoing support. For Faulkner and Bassett (2010), the challenges extend to include funding and bureaucracy and the challenges associated with professionalising peer support.

3.1 Benefits of peer support

Similar themes arose from the survey respondents and the project interviewees about the benefits of peer support. Although it can be difficult to pin down tangible outcomes, people talked of a wide range of benefits from personal to social and collective benefits through to benefits to services, staff and peer workers.

In the project interviews, a different emphasis was given to different benefits depending on the nature of the project, enabling us to understand more about the benefits of peer-led peer support within specific contexts and communities. Most of the benefits to peers/service users are directly related to the fact that peers are able to draw on and share their own experiences in order to inspire, model, support and inform others in similar situations.

Personal benefits

People talked of finding empowerment, finding a voice, increased confidence and self-esteem, dignity and respect and acceptance. They talked of finding a source of hope and optimism, companionship and friendship and reduced isolation.

“...being part of a group that understands and watch out for each other gives me a sense of belonging”

“Confidence, validation, hope for the future. I did feel somewhat isolated and depressed until I found Speak Out Against Psychiatry where I have found real support and understanding and I now have much more confidence to speak my truth about my experiences in psychiatric services.”

“A freedom to be, the chance to dream and thoughts of where I can go.”

In addition, several of the projects with peer workers emphasised the value of role-modelling in inspiring service users with hope and optimism. For Wish, the peer workers are acting as role models for the women in prison, enabling them to see that it is possible to have a job and a life; that these things are not out of their reach. Similar views were given about the two services offering peer support to people on inpatient wards, suggesting that one element of role-modelling is to introduce the idea – and the hope – that there are possibilities and options beyond their current situation.

Collective benefits

Being part of a group gave people a sense of mutual understanding, shared identity, shared experiences and a sense of belonging. People also talked of what the group could achieve together: challenging the status quo, collective action/campaigning, of finding strength in numbers, political commitment. Some talked of questioning the medical model of psychiatry and mental health, of finding mutual sources of information, creating new knowledge (of recovery, wellbeing etc.).

“...opportunity to link with people I might not come across otherwise, opportunity to get together to test out thinking re mental health and other issues, opportunity to get together and strategise and campaign for social change, especially regarding inequalities.”

In addition to this are the collective benefits derived from being in a mutually supportive group with a shared identity or identities: the sum being greater than the parts. For example, members of KTC valued both being ‘black people together’ and the focus of the group on exploring their combined creativity: on what they can achieve together, as well as being able to talk about things that people with a shared identity can be trusted to understand.

“The fact that this is a BME group takes it beyond mental health. Mental health groups can offer some things, but the specific experiences of being black survivors are very important. It is not just the experience of mental health issues that has had an impact on our lives, but the fact

that we are black people with those experiences. While other groups may offer compassion, this specific experience adds something to it.”

A collective focus on achieving something positive together, or of helping each other in positive ways, was also mentioned by Peer Support Network St Helens and Re-energize.

Practical benefits

Some people talked of practical benefits, such as accessing information and advice, learning new skills and strategies and signposting to other sources of help and information.

“It is good to talk to people who have similar experiences and also gain a lot of information about mental health and services.”

Social benefits

People talked of increased social networks, of social inclusion/integration, becoming involved, productive citizens, of challenging stigma and discrimination and of achieving a sense of justice and equality in society.

Re-energize, as a community-based mutual support group, emphasised its role in enabling social inclusion/integration and reducing the isolation of its members.

“We have organically, over time, increased our confidence to leave traditional mental health support and we have formed social and supportive networks to enable us to access the wider community.”

Benefits for peer workers

Peer workers identified benefits including employment, a greater understanding of their own situation, an opportunity to challenge barriers and stigma/discrimination and increased self-esteem and confidence. Reynolds and Seebohm (2010) identify similar benefits for the peer workers (ward visitors) at Canerows and Plaits. They talked of personal benefit and emotional reward from the visits, and of realising how far they had come and how valuable it was to be able to give something back to others.

Benefits for services and staff

These included the development of alternatives to mental health statutory services, increased knowledge of Recovery and new ways of achieving social inclusion, working in partnerships, and improved clinical practice through input to policy and practice development.

Reynolds and Seebohm (2010) also report that staff were very positive about the Canerows and Plaits service; they talked of the ward visiting service complementing their own work, said that visitors engage well with service users on the ward, and are of particular value for people who have no visitors and for BME service users.

3.2 Challenges

Again, there are many similarities between the survey participants, the peer support projects and the literature in the nature of the challenges identified. However, there were also some areas of difference, often relating to the context and nature of the peer support on offer. For example, the challenges of boundaries and role clarity tend to arise in relation to more formal approaches to peer support, whereas the challenge of professionalisation arises in relation to smaller voluntary sector groups and organisations offering informal peer support.

Institutional challenges

Institutional challenges were predominantly those associated with working as a peer worker within a statutory setting. People described professional resistance and a lack of power, a lack of value or recognition for peer workers and a struggle to find appropriate management support and supervision.

“Resistance from professionals to work in partnership, not having the same power, resources or influence of professionals to influence change and professionals trying to take over or thinking that we are there to assist them!”

As an example, Wish was at one time providing a peer support space to enable women to be in control and have a voice in policy implementation within a hospital unit. However, the resistance they encountered eventually caused the project to close.

“The corridors of power were just impenetrable. It was really disappointing for women and Wish decided they could not carry on with the project. It was hard going to the units and not achieve anything.”

In addition, concerns were raised about the tendency to view peer workers as ‘cheap labour’; that the role might be at risk of becoming diluted or lost within a statutory setting facing cuts and staff redundancies.

“Peer support is not a substitute for good professional support. It complements the professional with the personal but it can’t or should not be expected to bridge gaps in professional care and support.”

Reynolds and Seebohm (2010) in their evaluation of Canerows and Plaits identified a number of areas for improvement (rather than challenges), which included communications and relationships with staff. One of the early difficulties identified by CAPITAL concerned data collection: both finding suitable ways to collect the information and in relation to providing evidence for the strong impression that the project was succeeding in its aims.

Psychological and emotional challenges

Several people pointed to the psychological or emotional challenges of providing peer support, particularly if feeling vulnerable yourself.

“Peer support can be a mentally challenging job and it is important that there are things in place to support the peer.”

When they first started ward visiting, peer workers in Canerows and Plaits (Reynolds and Seebom 2010) found it hard to encounter people in severe distress, as this could trigger memories of their own feelings and experiences. Several of the projects mentioned the challenge of providing adequate support and training for peer workers in the context of talking about the mental and emotional challenges of the work and its potential to trigger personal issues.

Ockwell et al (2011) in evaluating the first six months of CAPITAL’S inpatient peer support service, examined some of the challenges encountered in setting up the project. For example, adjusting to being on the ward as a peer worker instead of a patient and to employment after long periods of unemployment were challenges for the peer workers. CAPITAL emphasise the importance of building in strong support and supervision for peer workers, both in the light of the emotional challenges and to support people unused to employment.

Clash of values or ethos

A clash of values or ethos might arise within a group or between a peer worker and service user. For example, someone might have fixed ideas of what works or does not work for them and can be unwilling to tolerate another point of view. In a group context, finding a balance between different views or between listening and taking action can present a challenge.

An issue raised by one interviewee is that peer support workers in a statutory mental health setting may be expected to work with anyone who comes to them, which might be a real challenge if your personal values and beliefs clash. Whilst this may be dealt with in supervision in this setting, it is something that peer support as a whole needs to address in developing its principles and values.

Resources and funding

Several projects and survey participants mentioned the challenges of resources and funding, particularly smaller group-based projects who were concerned about their concept of peer support becoming marginalised by an emphasis on more formal approaches.

“Financial and other resources to support development. Finding a place to meet. Access to training to build the group and to become sustainable.”

“Funding within a healthcare system that relies on a medical model.”

Professionalisation of peer support

This leads to another source of anxiety for both some survey participants and many of the projects: the professionalisation of peer support. Concerns were expressed about community, peer-led and informal approaches becoming subsumed by the models of peer support being promoted by mental health services: employing peer workers as part of existing mental health teams. Without the user-led base or ethos that sustains them at present, some raised the issue of how to retain the values and principles that make peer support different within a statutory mental health setting.

“...peer support will just be fitted into the all-pervading medical models of working rather than be considered a way of exploring other models of working within mental health.”

Survey participants and projects raised concerns about how to preserve the role of peer worker in a situation where they may be subject to NHS staff policies and procedures: for example, potentially having to undergo control and restraint training, getting involved in risk assessment, or being required to fit in with the predominant medical model.

Concern was also raised about how peer support workers will be recruited. Canerows and Plaits, for example, wondered whether peer workers employed within services may have to be able to demonstrate their level of ‘recovery’ or undergo particular training. Their peer support initiative attracts people not long after being discharged from wards but well enough to engage with people wanting to become peer supporters. Their concern was that professionalising peer support may mean these people missing out while “those who are already on their way to being ‘professionals’” becoming peer support workers. This issue of a ‘hierarchy’ of peer supporters was mentioned by survey participants as well.

Of equal concern was the possibility that peer workers might become ‘cheap labour’ replacing redundant staff, and that they might lose the distinctness of their role if employed within mental health services as part of a conventional team.

Concerns about the professionalisation of peer support feature powerfully in the consultation, especially for smaller user-led organisations where peer support may have a number of different manifestations. Repper and Carter’s (2010) review, with its focus on ‘intentional peer support’ proceeds on the basis that peer support workers will be employed within mental health services and that professionalisation is therefore a given. It becomes a valid role and provides employment for people who may wish to use it as a stepping stone for further employment opportunities. How that will affect other contexts and manifestations of peer support and those involved in such support needs to be carefully considered.

4. Training and Support

Training and support were raised as challenges for the development of peer support by many people, partly due to their resource implications but also due to accessing relevant and meaningful training and support. In the context of peer support roles within mental health services, Repper and Carter (2010) argue that with the formalisation of peer support roles comes the need for some standardisation in terms of values, skills and knowledge base in order that they are able to fulfil a distinct role with competence. They report a number of common themes to the training courses they identified:

- Recovery (and personal recovery planning),
- Peer Support (what it is and how it is distinct),
- Code of Conduct, ethical issues, per relationships and boundaries,
- Active listening skills,
- Recovery language,
- Problem solving,
- Understanding difference (including different experiences – voices, paranoia, anxiety – and diverse cultural, ethnic and religious backgrounds).

They found that the leadership of the training by peers who themselves have lived experience of distress was of considerable importance, in order to retain the lived experience approach with a focus on Recovery. There is, however, little in the literature on the needs for training or support coming from the more informal approaches to peer support within user-led groups and organisations.

This section is based on a combination of the survey responses, interviews with peer support project representatives, supplemented with information from interviews with Torsten Shaw (Making Waves, Nottingham), Steve Gillard (St George's, University of London), Karen Machin (Peer Support Network St Helens) and Raza Griffiths (Supporting Wellness and Personalisation – SWAP – peer brokerage training in Kent).

4.1 Training

The wide variety of views on what constitutes peer support and how people saw their own work and involvement was reflected in the descriptions of and views about the training received to work as a peer supporter or to offer peer support to others. Of the 34 survey respondents who expressed their views about training, only five reported having received specific 'peer support' training. Of these, one worked as a paid peer worker, one as a member of a group and three as volunteers. Two had received accredited training through the Open College Network and the other three had received intentional peer support training. Other types of training mentioned by survey participants included:

- Training in listening skills [...a six week induction to listening, which we also revisit often, so we evaluate our own listening skills and issues.]
- Egan's three stage model and other training in counselling
- Training in communication skills
- Training in mental health, including looking after one's own mental health and wellbeing
- Training in running groups/organisations which included chairing, equality and diversity, health and safety and safeguarding adults

People also spoke about bringing transferable skills from their education and work experience, together with their experience of mental distress, to their work in supporting others.

“I used to work in mental health as a support worker and tenancy support administrator for many years before I became unwell. I use those skills from my work experience.”

“I was once a volunteer mental health advocate and I received training in listening and rights in order to do this work. Now I draw on my own experience of psychiatric services and mental distress to help others.”

The overall impression is that there was not much experience of or need for specific training in peer support, but that what people valued is to learn how to listen, communicate and empower others and oneself. This connects with the view about peer support being values-based rather than specifically skills-based. There was also a strong view that ‘experience’ was qualification enough, primarily the experience of mental distress, having used services and of moving on with one's life (‘recovery’).

“Peers know how to talk to one another without being trained. It's normal!”

“Not sure what you mean by peer support – no training received which contains the words peer support.”

The value placed on training by the peer support projects is also closely related to their approach to peer support, in that where peer workers are employed it is given greater attention. However, not all of the projects with paid peer support workers offer or access training directly for their staff; several commented that they would value being able to access affordable and relevant training.

Roads to Recovery is the only project we spoke to who had accessed the ‘intentional peer support’ training provided by the Institute of Mental Health in Nottingham. However they currently have one peer worker in place who has not had training.

Both CAPITAL and Canerows and Plaits (providing a service to people on inpatient wards) provide training for their peer workers. Canerows and Plaits has developed its own accredited training which involves listening skills, personal skills, values and principles of user-led practice, understanding recovery, cultural and diversity issues.

CAPITAL buys in a course on mentoring which is 'not a perfect fit' and they would like to see a course for people delivering peer support on inpatient wards. They do give their peer workers what they describe as 'heavy induction', introducing them to the ethos of the organisation, the nature of peer support and the environment they will be working in. They also ensure that new peer workers meet those already in post (often on different sites) in order to learn from them.

In the longer term, CAPITAL would like to develop a course tailored for providing peer support for inpatient care. Some core elements would be the same as for any peer support training, but it would need to address such issues as ward politics, quick turnover, keeping people safe. They would like to develop the peer workers' consultancy role by involving them in the development of the training.

Rather like CAPITAL, Wish would like to be able to access more relevant training. They provide induction training for their peer workers, which includes weekly sessions for five weeks to introduce the organisation and its ethos. MindOut recruits peer workers to have the required group facilitation skills already; again they do not offer training but occasionally access additional training where required.

The remaining group-based peer support projects expressed less interest in training as it was less relevant to their mutual support ethos; indeed Re-energize has deliberately avoided it as it would go against their ethos of equality and mutuality. However, they did express an interest in accessing peer support training if it could be provided for all of its members in order to retain their ethos. KTC's initial activity, writing and performing a play, was supported by theatre workshops delivered by a black theatre company. Kindred Minds bring in training as and when they need it; for example, a one-day training on empowerment was provided by SIMBA, another black user group.

The few people we spoke to who had some experience of the nationally accredited peer support training developed in Nottingham felt it was important to include some form of grounding in the history of the user movement, of user involvement and/or of user-led values and ethos. There was some agreement that insufficient focus is given currently to diversity and equality issues. The themes addressed include: recovery, awareness of the medical model (enough to know that this is not what peer support is about), using positive language and reframing things, listening skills including reflective listening, research skills, recovery action planning etc. It runs over 10 days with one day on issues of difference and diversity.

Making Waves, a small peer run organisation in Nottingham, was involved in developing peer support training with the Institute of Mental Health. At the time of writing, the course costs £16,000 for the 11 day course which makes it inaccessible to small voluntary sector groups and user-led organisations. According to Torsten, Making Waves has since parted company with the Institute over issues of cost and attempts to strip the training of a critique of psychiatry. It retains a substantive but non-accredited training course which it could offer to others, but has found people

are not willing to take up an unaccredited course, despite it being offered at considerably reduced costs. Accreditation has become important because that is what the NHS has demanded thereby reducing the value of non-accredited training.

There were different views about the value of accreditation for peer support training. For example, Torsten Shaw pointed out that peer workers on the above course need to write a 2500 essay in order to get the qualification, which many people were put off by and could be seen as irrelevant to the actual skills needed by peer workers. Accreditation would have value if it involved supervised placements to see how people interacted, rather than testing people's essay writing skills. Karen Machin pointed out that accreditation could help in two ways. Within the NHS, without accredited peer support training, there is the danger that existing staff may be appointed as peer support workers, so re-badging existing posts (indeed there is some evidence that this is already happening). Secondly, accreditation is a way of appreciating and acknowledging people's skills and training, potentially boosting confidence.

However, as is reflected in the experience of Making Waves (above) there were people who felt that accredited peer support training might create a situation where informal approaches to peer support are seen as less valuable, thus making them less likely to attract funding from local commissioners. It could also potentially create a 'hierarchy of expertise' based on the kind of training people have received.

Raza Griffiths talked about training in peer support brokerage. For Raza (and for others), peer support is about de-professionalising distress and focusing on people's talents and skills, and the resources within themselves and in their communities. Peer support brokerage is about enabling people to see what resources exist within themselves and communities and how to use them in their recovery journeys. The brokerage training is a six day course over seven days, and covers:

- Broad context and values of peer support brokerage
- Service user movement and independent living movement
- Contexts and concept of personalisation
- The idea of choice, control and recovery
- Process of accessing personal budgets
- Developing support plans and creative ways of doing this
- Skills needed for working as peer support brokers

Overall, there was a strong sense that training needs to address the values and ethos of peer support with a grounding in the history of the service user movement and origins of peer support; as Torsten Shaw said: "we did not want peer support to be seen as having come out of nowhere."

Crucially, many people talked of the need for more training on diversity and equality and often saw this as an add-on to a course, but often did not or had not addressed it

for various reasons. It may be that what is needed is to discuss identities and experiences beyond mental distress in training: something like ‘purposeful diversity’ to address the different identities someone might come with. In many ways this is at the core of what peer support is about.

4.2 Support and supervision

Support follows similar lines to training, in that a higher emphasis is given to it in projects where peer workers are distinguished from service users. Otherwise, people saw this as more fluid and informal, as demonstrated by the following quotation:

“Peer support itself needs support. My experience tells me that groups can be particularly helpful in forming a small natural community, offering support in sometimes very different ways and providing a confidential and informed listening ear. Peer support also happens at different levels – from the informal peer support of a ‘drop-in’ group through to sometimes very skilled and specialist support when the individual needing support and his or her peer supporter are facing major challenges.”

Support to peer workers is considered of crucial importance by CAPITAL, Roads to Recovery, Wish, MindOut and Canerows and Plaits. Projects offered support in a range of ways: one-to-one supervision, de-briefing sessions, group supervision and enabling the peer workers to support each other. A couple of these projects highlighted the importance of supporting peer workers well, and of allowing for the resources, both financial and personal, to do this.

“One of the fundamental learning points is to reiterate the importance of the peer workers’ wellbeing.”

People talked of the value of support to enable people to manage their own stress and distress in relation to providing peer support, to manage issues relating to boundaries and role clarification, and in relation to supporting issues of shared identity. For example, Kindred Minds actively seeks out external supervision and peer support for their workers because, as a black project within a white organisation, they see this as necessary for supporting their service user staff. It may be that organisations need to be aware of the possibility of a mismatch between what they can offer and what the staff may need. Also, some peer workers may not have been in employment for some years, so may need support and supervision in relation to working or returning to work in an organisational context.

It was considered particularly important for peer workers working within statutory services to have independent and, if necessary, external support from service user(s) working within a user-led ethos.

“Extremely well supported by someone external to the programme who is able to offer supervision similar to that given to therapists, if needed. In addition, every supporter should be teamed with someone more experienced who is able to act as their mentor.”

One of the issues to emerge from these discussions was the value placed by some of these projects on encouraging the personal development of their peer workers. Roads to Recovery places a considerable emphasis on encouraging peer workers to think about and work towards their personal development. Similarly, CAPITAL talked of encouraging peer workers to take on roles in user-led organisations. Wish talked of training the women to become trainers and of encouraging those receiving peer support to become peer workers: a continuous programme of development. This raises the question of whether it might be possible to develop a viable career path for peer workers.

4.3 Support to projects and groups

Mostly we have talked about support to peer workers here, but another issue of crucial importance is the different types and levels of support that might be required by small user-led groups. Some people in the survey touched on the need for financial support and support and information from commissioners to enable them to take part on an equal footing with other organisations.

One of the issues that emerges from examining the sources of funding is whether or not this impacts on the nature of the service provided. We are not able to comment on the implications of this fully. However, as an example, CAPITAL has a contract with the local PCT to provide peer support to people on inpatient wards. They might not have done this without the contract, but it enables them to extend the nature of their service and to build a relationship with the PCT. They remain firmly independent of the statutory services, and retain their ethos and values from the user-led organisational base.

Clearly, without independent funding and depending on the nature of the service, it can be vital to build a good relationship with local commissioners. This will become more difficult over the coming year as the commissioners change. CAPITAL has this relationship with the PCT in West Sussex – hence their considerable funding for the next financial year (although this situation is likely to change with the change in commissioning bodies). Roads to Recovery, in their literature, mention the importance of support gained from a local professional acting as mentor and from a range of other local service providers. They have received statutory funding but found that in the new commissioning picture, they were too small an organisation to apply alone. They therefore teamed up with another local organisation in order to apply for core funding again from the NHS Trust.

5. Good practice

As we have seen, the descriptions of peer support and views on the values and ethos have already highlighted several themes that are considered good practice in service user-led peer support in mental health. This section discusses some of these elements in detail.

5.1 Preserving the value base of peer support

Both the survey participants and the projects we interviewed underlined the need for peer support to be based in personal experiences and seeing peers as ‘experts by experience’. There also has to be the acceptance that this ‘experience’ is diverse and different and peer support work must find ways to deliver on this diversity and difference. Along with acknowledging that experience can be a valid expertise, there needs to be a firm belief in people’s ability to take control of their lives, if given the support, encouragement and resources that they need.

“...it needs human interaction, human touch. It requires relinquishing power, stepping back and finding out about the ethos of working in a shared environment, where enabling people is more important than executing guidelines and policies.”

This idea of the ‘human touch’ or ‘humane care’ came up again and again. The ward visitors at Canerows and Plaits feel that this is the aspect that they take into the ward to the people they support.

“The only real care that the staff can give is your medication, making sure you sleep, get up at a certain time etc. The other kind of ‘human’ care, of sitting and talking to you, finding out what you need and making sure the small things that add to wellbeing are taken care of – these come from other service users who have been in the same situation as they have.”

This sentiment was echoed by survey respondents too.

“The thing most lacking in the UK mental health system is compassion. The amount of paperwork that nurses are required to do is ridiculous and results in their having no time to talk to the patients, yet diagnoses and medication are based on their observations which is absolute nonsense. Peer support workers will have the time to talk and find out that is worrying a person ... and hopefully could help sort out these problems or direct them to an appropriate agency.”

A recent inquiry into crisis and acute care in England and Wales (Mind 2011) found that the most important things that people wanted from care services are humanity, choice and control. Humane care is based on compassion, empathy, a non-judgemental attitude, the ability to listen and support accordingly, and enable an environment in which people can flourish.

5.2 A structure that supports organic development

As we have seen in the discussion on the challenges of peer support, the issue of boundaries came up several times. There seemed to be some agreement, especially among those involved in more formal approaches to peer support, that peer support needs certain boundaries so that everyone involved is protected and can work in a safe environment. MindOut, for example, says:

“There are endless boundary issues when you all have something in common; we have constant struggles with boundaries. It is testing. For peer support to work in mental health, think it has to be well held, safe enough for people to explore their issues.”

Road to Recovery also echoed this sentiment:

“We are firm about what it is: it is not counselling, not therapy. If there is no structure, there may be undue pressures on the supporter and the service user may not feel safe.”

However, there was also the feeling, especially among those involved in peer support relationships which were mutual or where there was no clear demarcation between peer supporters and those they supported, that these boundaries should not be in terms of policies that disable the organic and evolving nature of the peer relationship or in terms of ‘red tape’. What was needed, according to one survey participant, was “informal formalities, finding the right balance or relation.”

In group situations, as with any group formation, it was felt that it is good practice to be clear about what can and cannot be achieved through the relationship.

“Ensuring there is discussion about agreed goals/outcomes at the beginning and reviewing this frequently.”

“People around that have an understanding of looking after themselves and what they contribute to the dynamics of the group, to be self-reflexive and be able to allow diverse relationships.”

Overall, the feeling is that agreed upon boundaries could be beneficial to the peer support relationship as long as it does not impinge on the natural, organic growth of the peer relationship.

5.3 Service users leading peer support

The participants in this consultation are all in agreement that good practice in peer support will ensure that those who are involved will have the right and the opportunity to influence and act upon agendas and decisions regarding the delivery of peer support. That it is user-led is one of the fundamental principles of peer support, as we have seen.

Several of the projects (e.g. Canerows and Plaits, Kindred Minds, CAPITAL, Wish and MindOut) emphasised the importance of having an organisation with a user-led

ethos, values and principles as a base with which to support and strengthen the peer support project. The organisational ethos gives them the strength to remain independent of statutory mental health services, particularly where they are working in and funded by those services.

Good practice in peer support will also ensure that the work happens in partnership with professionals rather than being taken over by professionals. It was also felt that peer support will work well if based in social models of mental health and not in a medical model and that policies, practices and priorities need to be driven by service users and not professionals.

However, losing the user-led nature of peer support is also one of the main things that people are worried about. In a context where there is a clear move towards appointing peer support workers within statutory sector services, it is difficult to see how much influence they will have on organisational practices and policies and how peer support becomes entrenched in mental health care (see also discussion in the 'benefits and challenges' section). Kindred Minds, for example, fears that:

“... it will get taken over and will need to be fitted into the existing modes of working within mental health services rather than services changing practices to make it more in line with the peer support ethos... There is also the fear that peer support will just be fitted into the all-pervading medical models of working rather than be considered a way of exploring other models of working with mental health.”
Preserving the variety and range of peer support

We have seen that peer support happens in a range of contexts and in a variety of different formats, involving several different models. Good practice in promoting peer support will ensure that this wide variety is preserved and not lost in the move to professionalise peer support. Indeed, several projects are delivering peer support in more than one way precisely to ensure that the diverse needs of the people they work with are met.

5.4 Preserving the variety and range of peer support

We have seen that peer support happens in a range of contexts and in a variety of different formats, involving several different models. Good practice in promoting peer support will ensure that this wide variety is preserved and not lost in the move to professionalise peer support. Indeed, several projects are delivering peer support in more than one way precisely to ensure that the diverse needs of the people they work with are met.

5.5 Providing good support and resources

The views on 'peer support training' differed based on whether or not people worked in formally structured ways or in more flexible and organic ways. However, there was a wide agreement that supporting peer supporters in their work is an important element of good practice. There were several good practice examples of how this

was done in addition to organisational management structures such as supervision. These included external peer supervision, opportunities to talk to other peer supporters, issue-based training in looking after oneself, listening skills and working with differences and diversity.

“Extremely well supported by someone external to the programme who is able to offer ‘supervision similar to that given to therapists, if needed. In addition, every supporter should be teamed with someone more experienced who is able to act as their mentor.’”

Good practice also involved adequately resourcing peer support projects, not thinking of it as a ‘cheaper option’, valuing people’s work through payment and freeing them up to use their expertise in supporting others rather than focusing on organisational development issues.

“Adequate and ring fenced financial support. Peer supporters should not also be expected to fundraise and where they are taking on formal duties, they should be paid.”

“Commissioners should be supporting peer groups by providing them with strategic planning information linking them with local and national networks, finding venues and resources as well as financial support. Paying service users for doing the work and leading the support group and encouraging volunteering opportunities for other peers.”

6. Preserving peer support: future work

As we have seen, peer support covers a range of different contexts, activities and ways of working. The history and development of peer support encompasses self-help groups, mutual support groups, the user/survivor movement, the growth of survivor activism, self-management, and what is often referred to as ‘intentional’ peer support. To date, this literature has not been brought together in any one place and there remain some significant gaps in our understanding. While there are overlaps between these different areas of development and the associated literature, there are also significant issues of tension and dissent which may be in danger of widening the gaps.

Repper and Carter (2010) usefully bring together the international literature on peer support involving the employment of peer workers, widely accepted as ‘intentional peer support’, in mental health services. In their introduction, they refer to reviews that have addressed other areas, for example, self-help/mutual support (Raiff 1984; Pistrang, Barker and Humphreys 2008) and peer-run services (e.g. Davidson et. al. 1999; Galanter 1988; Humphreys 1997).

6.1 Going beyond the mainstream

The works referred to above have looked at peer support from its basic principle of support (mutual or otherwise) for and by people with a shared experience of mental distress. We have shown that, for many people, peer support also encompasses other shared identities, experiences and backgrounds. The literature on the development of the various contexts of mental health peer support for people from marginalized and minority communities remains largely unexamined.

In an article exploring the similarities and differences in the ways in which the terms ‘self-help’, ‘peer support’ and ‘service user groups’ are used, Seebohm, Munn-Giddings and Brewer (2010) address the historical, cultural and social factors that have led to similar developments within African, African-Caribbean and other black communities. They argue that:

“There is a strong tradition of self-help within Black communities, where there is an emphasis both on the individual helping him or herself and on people helping ‘their own’, identified as the Black community or sometimes as the neighbourhood, school or church community.”

Self-help and peer support groups within racialised communities have developed as a direct response to the lack of culturally specific services in the mainstream (Wilson 2001) and often as part of broader community development initiatives (Seebohm et al 2005). Literature examining service user involvement (Blakey 2005, Kalathil 2011a)

or the meaning of recovery (Trivedi 2010, Kalathil 2011b) from the points of view of racialised communities, have shown that there are different understandings and ways of working that are not often captured in popular scholarship, and that these need to be considered when developing policies and practice priorities.

Our conversations with the projects involved in providing peer support to specific communities underlined the importance of this. MindOut (providing support to mental health service users from LGBT communities), Wish (supporting women within prisons and special hospitals), and Canerows and Plaits, Kindred Minds and KTC (all working with people from black and minority ethnic communities) spoke of the need to attend to the specific needs of their members, often not catered to in service delivery. Clearly, there is a need for a more sophisticated understanding of the nature of peer support where it concerns people with experiences of marginalisation. It is important to remember that social justice movements and initiatives have an inherent danger of allowing the narrative of a given group to be dominated by individuals who are normative in all other senses, thereby marginalising non-normative voices within the group.

6.2 Valuing peer support in all its variety

Faulkner and Basset (2012) explore peer support in relation to its historical roots within self-organising service user groups and service user activism. They also point to the value of peer support in creating new knowledge. Both Faulkner and Basset (2012) and Seebohm, Munn-Giddings and Brewer (2010) highlight the dangers inherent in the current developments that favour a particular model of 'peer support' that helps services "to meet their statutory requirements for community engagement or providing an alternative to statutory provision" (Seebohm, Munn-Giddings and Brewer 2010): developments that may result in the dilution and, possibly, the disappearance of many community-based self-organising groups.

At this point it seems important to mention the work of Steve Gillard, whose team at St George's, University of London, is researching peer support in relation to peer workers in the NHS and in the voluntary sector.⁴ They are doing 12 case studies, some in the voluntary sector, and some in the NHS with several being partnership projects. Two are specific to black and minority ethnic communities. The focus is on learning from the NHS as this is the funding source, but the team believes it is important to include work in the voluntary sector as there are many examples of where the voluntary sector is doing peer support.

In some ways, it is understandable, given the policy direction, that current focus in research, training development and other knowledge production is on how peer support works within the NHS. However, we have seen that there is a great diversity within peer support groups and activities and it is important that equal attention is

⁴ 'Peer worker research project: new ways of working in mental health services, assessing and informing the emergence of peer worker roles in mental health service delivery'. The study commenced in July 2011 and will run for 21 months, and involves a number of voluntary and statutory sector partners. For more information, contact Steve Gillard at sgillard@sgul.ac.uk or 020 8725 3614.

paid to how these contribute to the wellbeing of people who have mental health needs. There needs to be more investment in exploring peer support in all its forms and supporting community based peer support initiatives with more funding and resources.

6.3 Exploring the impact of professionalisation

Valuing people with lived experiences of mental distress as an important part of the mental health work force is indeed a step in the right direction in a recovery-oriented mental health service. However, our evidence also shows that there are several concerns about the impact of professionalisation which need to be explored further. In some literature, the peer employed to provide support “is generally considered to be further along their road to recovery” (Davidson 2006). It is not clear whether professionalised peer support posits a particular model of recovery, one where it is a linear path from illness to wellness, with different people occupying different positions: a definition of recovery far removed from those that have arisen from the survivor movement itself. Perhaps the most important concern is how peer support will fit into organisational structures, policies and practices that govern a mental health system that continues to be based on medical models, and where compulsion, coercion and a focus on risk are part of everyday practice.

We have also highlighted the financial problems associated with accessing accredited ‘intentional’ peer support training that members of smaller organisations and individuals wanting to be peer supporters may face. This is especially pertinent as it is a familiar scenario that has been identified and discussed in relation to advocacy. The implementation of independent mental health and mental capacity advocacy through the amended Mental Health Act made it mandatory that all advocates wanting to fulfil this function should qualify as accredited trainers within a year of practice. This put up barriers for advocates from smaller organisations and from marginalised communities where organisations have been historically under-resourced (Falconer 2011), one of the contributing factors to the limited success statutory advocacy has had in meeting the needs of people from black and minority ethnic communities (Hakim and Pollard 2011).

There is also a need to look more closely at the content of existing accredited training. While there is an agreement that peer support workers need to have a good understanding of diversity and difference in order to work well, there is also evidence to suggest that current training may not address these issues adequately, or may too often do so as an ‘add-on’ rather than addressing them as an integral part of preparing to work with the wide diversity of people who access mental health services in this country. It seems more than possible, given the much-discussed failures of mental health services in meeting the needs of marginalised groups, that peer workers employed within mental health services will find it hard to extend their work to these groups unless given specific remit and resources to do so.

Our consultation also shows that there are concerns about how professionalising peer support will affect community based, organically evolving and issue-focused peer support. There needs to be more exploration into this given that community support structures are already affected by cuts in public spending.

6.4 Making a business case for peer support

Analysing the economic benefits of peer support was beyond the scope of this consultation. Overall, there is considerable consensus about the benefits of peer support in its many different contexts, as we saw earlier. Its 'effectiveness', however, is more difficult to prove, as the benefits of peer support are felt more at an individual, 'lived' level, not necessarily quantifiable in economic terms. Repper and Carter (2010) show that whilst existing randomised controlled trials did not show that peer support workers made a difference to the mental health outcomes of people using services, an examination of a broader range of studies show more apparent benefits:

“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; and social inclusion, engagement and increased social networks. It is just these outcomes that people with lived experience have associated with their own Recovery...” (p 17)

Indeed, the literature on peer support, and our evidence, shows that there are several benefits to people with similar life experiences supporting each other, ushering in more humane care, hope, optimism and the confidence and self-belief that can arise from seeing 'someone like me', whether one sees them as a role model or not. The 'Strategies for Living' research (Faulkner and Layzell 2000) records:

“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” (p 92-3)

There is more work to be done to consolidate the evidence for the effectiveness and benefits of peer support as it occurs in informal, mutual, self-help and peer support groups. It would be almost impossible and perhaps also undesirable to conduct a conventional randomised controlled trial of the benefits of being a member of a peer support group however.

6.5 Building social capital

It has been argued that self-organising groups “bring[ing] together people with a common interest (whether their distress is the focus or in the background) are likely to share the mutuality and reciprocity that builds positive social capital” (Seebohm, Munn-Giddings and Brewer 2010). Community social capital, it has been argued, “can affect community health through the diffusion of information on health, healthy behaviour norms, promotion of access to local social services” (OECD 2010) and is connected to promoting well-being and resilience (McKenzie 2006).

Regardless of what they are called – peer support, self-help, mutual support – these groups bring people together to support and sustain each other, often in the face of adversity and marginalisation. It is important that peer support is studied and promoted with an understanding of its history, development and significance for various groups and communities.

References

- Blakey (2005) Participation – why bother? The views of black and minority ethnic mental health service users on participation in the NHS in Bradford. International Centre for Participation Studies
- Bradstreet, S (2006) 'Harnessing the "lived experience": formalising peer support approaches to promote recovery.' *The Mental Health Review*, 11.2
- Corston, J (2007) The Corston report: a report by Baroness Jean Corston of a review of women with particular vulnerabilities in the criminal justice system. Home Office
- Davidson, L et al (2006) 'Peer support among adults with serious mental illness: a report from the field.' *Schizophrenia Bulletin*, 32.3: 443-450
- Davidson, L et al (1999) 'Peer support among individuals with severe mental illness: a review of the evidence.' *Clinical Psychology Science and Practice*, 6: 165–187
- Falconer, P (2011) 'Advocacy and black and minority ethnic communities.' *Open Mind* 165: 12-13
- Faulkner, A and Basset, T (2012) 'A long and honourable history.' *The Journal of Mental Health Education and Training*, 7.2: 53-59
- Faulkner, A and Basset, T (2010) A helping hand: consultations with service users about peer support. Together
- Faulkner, A and Layzell, S (2000) Strategies for living: a report of user-led research into people's strategies for living with mental distress. Mental Health Foundation
- Galanter M (1988) 'Zealous self-help groups as adjuncts to psychiatric treatment: a study of Recovery, Inc.' *American Journal of Psychiatry*, 145:1248–1253
- Hakim, R and Pollard, T (2011) Briefing 3: independent mental health advocacy. Mental Health Alliance
- Humphreys, K (1997) 'Individual and social benefits of mutual aid and self-help groups. *Social Policy*, 27: 12–19
- Kalathil (2011a) Dancing to our own tunes: reassessing black and minority ethnic mental health service user involvement (Review and Reprint edition). NSUN
- Kalathil (2011b) Recovery and resilience: African, African-Caribbean and South Asian women's narratives of recovering from mental distress. Mental Health Foundation and Survivor Research
- McKenzie K (2006) 'Social risk, mental health and social capital.' In K. McKenzie and T. Harpham (eds.) *Social capital and mental health*. Jessica Kingsley Publishers
- Mead, S (2003) 'Defining peer support.' www.mentalhealthpeers.com [Accessed 29th March 2012]
- Mind (2012) Listening to experience: an independent inquiry into acute and crisis mental health care. Mind

Munn-Giddings, C et al (2011) Effective support for self-help/mutual aid groups (ESTEEM). Interim report. Self-Help Nottingham, Anglia Ruskin University and the University of Nottingham

OECD, IRDES and CERI (2010) Social capital, human capital and health: what is the evidence? OECD

Ockwell, C (2012) What do patients think? A review of feedback from inpatients who have used the CAPITAL inpatient peer support service. CAPITAL Project Trust.

Ockwell, C et al (2011). 'You don't get this in other hospitals.' Inpatient peer support – the first 6 months. CAPITAL Project Trust.

Pacitti, R et al (2011) The first step: an exploration of how Croydon's black and minority ethnic communities access counselling services. London: Mind in Croydon.

Pistrang, N, Barker, C, Humphreys, K (2008). 'Mutual help groups for mental health problems: a review of effectiveness studies.' *American Journal of Community Psychology*, 42: 110-121

Prison Reform Trust (2010) Bromley briefings prison factfile. Prison Reform Trust

Raiff, N. R (1984). 'Some health related outcomes of self-help participation.' In A. Gartner and F. Riessman (eds.) *The Self-Help Revolution*. Human Sciences Press

Repper, J and Carter, T (2010) Using personal experience to support others with similar difficulties: a review of literature on peer support in mental health services. University of Nottingham & Together

Repper, J and Watson, E (2012a) 'A year of peer support in Nottingham: lessons learned.' *The Journal of Mental Health Training, Education and Practice*, 7.2: 70-78

Repper, J and Watson, E (2012b) 'A year of peer support in Nottingham: the peer support workers and their work with individuals.' *The Journal of Mental Health Training, Education and Practice*, 7.2: 79-84

Reynolds, D and Seebohm, P (2010). Ward visiting service and 'Have Your Say' forum evaluation. *Canerows and Plaits*

Seebohm, P et al (2005) *Together we will change: community development, mental health and diversity*. The Sainsbury Centre for Mental Health

Seebohm, P, Munn-Giddings and Brewer, P (2010) 'What's in a name? A discussion paper on the labels and location of self-organising community groups, with particular reference to mental health and black groups.' *Mental Health and Social Inclusion*, 14.3: 23-29

Trivedi, P (2010) 'A recovery approach in mental health services: transformation, tokenism or tyranny?' In T. Basset and T. Stickley (eds.) *Voices of experiences: narratives of mental health survivors*. Wiley Blackwell

Watson, E (2012) 'One year in peer support: personal reflections.' *The Journal of Mental Health Training, Education and Practice*, 7.2: 85-88

Wilson M (2001) 'Black women and mental health: working towards inclusive mental health services.' *Feminist Review* 68: 34–51

Women in Prison (2008) *Women prisoners: facts and figures*. Women in Prison

Appendix 1 – Online survey

Exploring peer support

Together, the national mental health charity, is conducting a consultation on peer support. We would like to hear your views on what you consider to be peer support, your experience of being part of a peer support group, either receiving peer support or offering peer support to others (or both). We would like to hear your views on informal peer support (through user groups, support groups etc. based in the community) and more formalised peer support services based in NHS organisations.

Please use the following survey to tell us your views on peer support. Please try to answer all questions, but feel free to skip any that you are not comfortable with. The information you give will be treated in confidence and anonymously; we will not publish any identifying information about you or your networks. The information from the survey will be used to write up a scoping report to develop effective peer support work.

If you have any questions, or want any further information about this consultation, please contact Alison Faulkner at alison.faulkner2@btinternet.com or Jayasree Kalathil at Jayasree@survivor-research.com.

Please complete this survey by **15th March 2012**.

Thank you for taking the time to complete this survey.

A. Defining peer support

- 1) In your view, what makes someone a 'peer' in relation to peer support in mental health? [Text box]
- 2) Is it important for you that a peer should share anything more in common with you than an experience of mental health problems/services? [Tick box]
Yes
No
Don't know
- 3) If you have answered 'yes' to question 2, can you tell us what additional characteristics or experiences you find valuable in a peer? [Tick all that are relevant]

Shared gender, ethnic background, sexual orientation, age groups, faith etc.

Shared understandings of specific diagnosis and their effects

D. About you

We are asking these questions to get a sense of the diversity of people using and offering peer support services and their views. This will help inform how future services need to be developed.

16) Age: [Text box]

17) Gender: [Text box]

18) Ethnicity: [Text box]

19) Sexual orientation: [Text box]

20) Religion: [Text box]

21) Do you have a long term health condition or disability? [Tick box] Yes/No

22) Are you: [Tick boxes] A mental health service user
 Former mental health service user
 Carer

Thank you very much for your time.

If you would like to be informed of the results of this consultation please give us your email or postal address. [text box]

Appendix 2 – Points explored in interviews and visits

Describe type of peer support project/service...

- What is it called
- User or peer-led? vs. base within organisation / employment by organisation – what type of organisation (voluntary / statutory / ULO...)
- One to one / group / virtual / mixture – or other?
- Employment / volunteer / mutual support
- Independence of services?
- Core values / principles you feel are important?
- General service or offered to specific community(ies) ?

Need for service

- What are the reasons for setting up the project
- How did the service originate – did you (need to) demonstrate the need for the service? If so, what was the evidence for it

Access and accessibility

- Who can access your service?
- Who *does* access your service? (are there any significant gaps in terms of BME communities, or marginalised groups...people you feel are not accessing it)
 - What reasons do you think some groups might not access your service?
 - Are you doing anything to reach specific groups or communities?
- Do you find that different methods of peer support reach different communities or groups of people?
- [more]

Who do you think is a peer?

- Is it enough that peers share a psychiatric history? – or do you find people wanting to meet people of the same age / gender / race / culture / sexuality / etc.
- If a one to one service – do you find that people need/want to be 'matched' on other characteristics than a shared psychiatric history?

Costs / value for money

- Do you have information available on how much the service costs to run / have you evaluated your service and can you make the results available to us?
- Who funds your service?

What is peer support?

- What exactly does your service (or do the peer supporters) *do* ... activities / locations / limits to activities /
- Are peer supporters and people who are supported separated – i.e. is it formalised in that way or informal, mutual but organised?

Training and support

- What sort of training / who delivers it / is it peer-led training /
- What is in the training – can you give us a list of contents/topics covered
- Nature of ongoing support offered to peer supporters

What would you like to be able to do with your peer support service if you were given sufficient funds?