

August 2012

Peer Support in mental health and learning disability

Summary

The importance of peer support - the help and support that people with lived experience of a mental illness or a learning disability are able to give to one another – is increasingly being recognised.

This briefing paper provides a short descriptive overview of peer support in mental health (including dementia) and learning disabilities, based on some of the recent literature, and highlights key messages from work being undertaken across the UK by the Mental Health Foundation. This work looks at how peer support can help people to recover, or get more control over their condition, and to live fulfilling lives in their communities. The briefing quotes the views of people who have both given and received peer support, and concludes with recommendations for the expansion of both informal and formal peer support.

Peer support can be provided in number of ways - from one patient to another in a hospital ward; by peer mentors or informal peer groups in the community; or by peer support workers formally employed by mental health or learning disability services to work alongside individuals.

The Mental Health Foundation is involved in a number of projects looking at peer support. These range across projects exploring peer support and mentoring for older people and people living with dementia, studies investigating how peer support might be useful for people with long term health conditions, and projects looking at how people with learning disabilities can support each other to make changes in their lives.

The key messages from the Foundation's work confirm what the literature suggests - the benefits of peer support are widespread, for the individual receiving the support, the person giving it, and for services. They include better mental health, an increased sense of wellbeing, increased confidence and learning skills, greater social connectedness, improved recovery and coping skills and fewer hospital admissions.

Both planners and commissioners of services need to be aware of the evidence around peer support in mental health and in learning disability and to build peer support into their future planning and commissioning cycles.

Background

'Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful' (Mead, 2003)

Peer support may be defined as the help and support that people with lived experience of a mental illness or a learning disability are able to give to one another. It may be social, emotional or practical support (or all of these) but importantly this support is mutually offered and reciprocal, allowing peers to benefit from the support whether they are giving or receiving it. The literature suggests that key elements of peer support include that it is built on shared personal experience and empathy, it focuses on an individual's strengths not weaknesses, and works towards the individual's wellbeing and (in the case of certain mental health problems) recovery.

Peer support has to varying degrees always existed among service users, with people providing mutual support to one another in institutional care, inpatient

services, day centres or support groups in the community. In mental health, peer support developed more formally with the creation of networks of self-help groups such as the Hearing Voices Network and MDF: The Bipolar Organisation (now Bipolar UK), both established in the 1980s to provide support to people suffering from specific mental health conditions. In the 1990s service user involvement in the design and provision of services was developed further in the UK, leading to increased recognition of the important role ‘experts by experience’ could play in mental health and learning disability services. The development of peer-run services and the formal employment of peer support workers has been pioneered in the USA, New Zealand, Canada and Australia, and in recent years the UK has begun to build on this work to increase peer support provision across the four national health and social care systems.

Recent reviews of the published literature on peer support (Repper and Carter, 2010; Williams, 2011) cite a range of papers describing the models of peer support that have been developed, and their impact. Broadly, there are three models, all of which are evaluated as having merit – informal and ad-hoc support among service users, which many find just as valuable as support from healthcare staff (or even more valuable); organised but unpaid peer support generally undertaken by volunteers who take on roles as ‘mentors’ or ‘peer buddies’; and paid peer support, where participants will generally be part of a team contracted to provide services to service users. In some cases peer support may be facilitated by a professional, particularly within learning disabilities and areas of mental health such as dementia, but the focus remains on peers sharing their experiences to help one another. However these models, though helpful, need to be treated with caution. The contexts and support that some service users describe as ‘peer support’ do not always fit into defined models (Faulkner and Kalathil, 2012).

The formalisation of peer support workers working within the mental health system is seen as a welcome growing trend, capturing the ‘expertise of lived experience’ that peer support is able to provide (Skills for Health, 2011; Stamou, 2010). However the evidence does emphasise that to be successful, formalised peer support requires a number of factors to be considered, including:

- clear role definitions
- access to appropriate training, support and supervision for peer support workers

- training and support for staff to ensure that peer support workers are fully integrated within wider teams (McLean et al, 2009).

‘Peer support is built on the recovery principles of inspiring hope, facilitating opportunity to make meaningful life choices and supporting others to take control of their own recovery’ (NHS Confederation, 2012)

Peer support in Government policy

In England there has been an increasing emphasis on the value of peer support.

The Government’s ‘Putting People First’ paper recognizes that ‘the availability of effective peer support is essential in the transformation of adult social care and in enabling people using services to have greater choice and control’ (Department of Health, 2010, p2). The English Mental Health Strategy of February 2011 suggests that peer support is one way in which local voluntary and community organisations can meet the needs of people experiencing poor mental health, and help people to manage their own mental health better in the community (Department of Health, 2011a, p35). In supporting documentation for the strategy the Government also acknowledges that ‘there is potential for improved quality of care and resource savings – in terms of both service outcomes (reduced bed days) and overall costs – from using the expertise of people with lived experience of mental health problems in the workforce’ and suggests that peer support is ‘one way for people with mental health problems to participate effectively in paid employment’ (Department of Health, 2011b, p47).

Peer support is not just seen as important to those with existing disabilities or mental health problems. The Government has described peer support as playing an important role in areas of prevention, health inequalities and public health as well. In its strategic vision for volunteering the Department of Health emphasises the health and wellbeing benefits of peer support for the individual and society, as well as the potential for cost savings. It believes peer support can provide ‘improved access to timely information, positive role models and greater community resilience and capacity for self-help’ which can result in increased prevention and early intervention in many health problems (Department of Health, 2011c, p14).

The Ministerial foreword to the new **Scottish** mental health strategy (Scottish Government,

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2012) states that “Self-help, self-referral, self-directed, self-management and peer to peer are all concepts that will only grow in importance and which demand a different mindset and approach to service design”. The Strategy notes that there is a demand for greater use of formal and informal peer support approaches, in addition to the peer support worker role within care teams, and makes a commitment to commissioning a review of work to date in Scotland on peer support as a basis for learning lessons and extending the use of the model more widely.

Since 2006 the Scottish Government has funded the Scottish Recovery Network (with support from the Scottish Development Centre for Mental Health / Mental Health Foundation) to implement a programme of work to enhance peer support services across Scotland, including:

- a pilot of six formalised peer support services for people with mental health problems across five Health Boards in Scotland (2008-2009)
- guidelines to support the development of peer support worker roles in the mental health sector (2011)
- a National Mental Health Peer Support qualification.

Together for Mental Health, **Wales’** draft strategy for improving mental health in the 21st century (Welsh Government, 2012) cites a service user comment, ‘Peer support schemes are what we need. You need someone who has been through something similar. They can give you advice’, and states that initiatives such as the development of peer support workers should be considered by statutory and Third Sector agencies as a means of improving the staffing skill mix within services.

In guidance recently produced by the Joint Commissioning Panel for Mental Health (JCPMH), peer support is recommended as part of a stepped care model for primary mental health care services, where ‘Peer mentors and patient experts can be employed in the primary mental health care team to work alongside patients. Experts by experience can coordinate and distribute information about self-management, co-ordinate mentorship programmes, and offer training and deployment of people with lived experience for specific purposes, such as advocacy’ (JCPMH, 2012a, p9).

The guide for commissioners of dementia services also recommends that peer support work should be commissioned as part of the support provided for people with dementia living at home or in a care home (JCPMH, 2012b, p11). The National Dementia Strategy for England (Department of Health, 2009) states that comprehensive community personal support service would provide access to peer support networks.

Benefits of peer support

“The benefits of peer support are clear, with shared identity, increased self-confidence, developing and sharing skills, improved mental health and wellbeing, accompanied by less use of mental health and other services” (Faulkner and Bassett, 2010)

The benefits of peer support are wide ranging for those receiving the support, peer support workers themselves, and for the mental health system as a whole and these have been described in a range of literature. The mental health charity Together outlines many of these benefits in its literature review ‘Using Personal Experience to Support Others with Similar Difficulties. A Review of the Literature on Peer Support in Mental Health Services’ (Repper and Carter, 2010).

One of the key benefits of peer support is the greater perceived empathy that peer supporters are seen to have for the individuals they support. This sense of empathy and respect often enables a more open and trusting relationship to be formed than other mental health and learning disability services may be able to achieve (Woodhouse & Vincent, 2006, p10). This relationship is vital for the empowerment of the individual to take responsibility for their own life or, in the case of mental health service users, their own recovery.

Empowerment can be achieved through the strengths-based approach of peer support which focuses on what the individual can do and their personal strengths, thereby ‘recognising the individual as a whole person rather than focusing solely on the problem’ (Scottish Recovery Network, 2011). As Campbell and Leaver write, ‘Peer programs empower people because their practice facilitates a grass-roots process...of self-efficacy, self-esteem, and the belief that positive personal change can come about through one’s own efforts’ (2003, p14).

Another important benefit of peer support is that it ‘produces hope, an element

indispensable to independent living and recovery' (Clay, 2005, p11). Peer support workers are able to 'model' recovery for service users (McLean et al, 2009, pii), showing them that they too are able to take control of their lives.

Peer support also has benefits for peer support workers themselves, increasing levels of self-esteem and confidence, and enabling them to feel like a valued citizen who is making a contribution to society (Woodhouse and Vincent, 2006, p11). Peer support workers in mental health are also able to increase their ability to cope with their own mental health problems, aiding their own continuing recovery (Solomon, 2004, p396). The skills learnt through working as a peer supporter can also make an individual more employable.

'The clear distinction between Peer Support Workers and other roles is the requirement of post holders to explicitly draw on and share their own experience of emotional distress and/or using mental health services in order to inspire, support and inform others in similar situations' (NHS Confederation, 2012)

One of the most important benefits for the health system as a whole is the potential decrease in hospital admissions for those engaging in peer support. Several studies on admission rates have reported positive results, for example, Chinman et al (2001) found that when comparing one peer support project to traditional outpatient care there was a 50% reduction in readmissions to hospital of people accessing peer support, with only 15% of peer support participants readmitted in the project's first year of operation. Other benefits for the health system include reducing the workload of overstretched staff (Repper and Carter, 2010, p11), and enabling the health system to reach people who might otherwise be hard to engage.

However it is important to recognise that peer support may not suit everyone (see the final two quotes set out in Annex A). A good personal relationship between the individual and the peer supporter is important for the success of the arrangement, but is not guaranteed. Boundaries between peer support and friendship may become blurred and hard to maintain. Some may find being part of a peer support group actually hinders their recovery by locking them into patterns of thinking and behaviour that they need to break out of; others may find it difficult to cope with the experiences of their peers; and it may deflect people from seeking alternative avenues of support.

The research is not always positive. One study evaluating the evidence on the effects on

health and social outcomes of computer based peer to peer communities and electronic self support groups failed to find robust evidence on the health benefits of virtual communities and peer to peer online support (Eysenbach et al, 2004).

There is also a danger that formalising peer support may 'steal' it away from service users who simply see it as a natural and spontaneous response to someone who has shared their own experience. By labeling people as peer support workers we may bureaucratise the process and lose some of the humanity that makes people want to help others simply for the sake of it. It has also been reported that smaller voluntary sector groups offering informal peer support see the professionalism of peer support as a challenge to their ethos and survival (Faulkner and Kalathil, 2012). Peer support must remain empowering, or else it could become impoverished.

Despite these concerns, the evidence of the benefits of peer support is strong. It suggests that peer support does need to be routinely offered to people with mental health problems, including dementia, and learning disabilities - but it must be the sort of peer support that people choose for themselves.

Mental Health Foundation work on peer support

The Foundation has been involved in developing peer support for a number of years, not least through service user-led research.

For example, Strategies for Living (a 2000 report of user-led research into people's strategies for living with mental distress) involved peer support for service user researchers who sometimes had no experience of doing research; and in 2002 it published a guide to setting up peer support in education settings.

The Foundation continues to be involved in a number of projects providing, promoting and evaluating peer support in both mental health and learning disability. This section highlights some of the key messages that have come out of this work.

A selection of personal comments from participants in the Foundation's peer support work, and the Foundation's Policy Panel, are at Annex A.

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Work in mental health

Brighter Futures, Scotland, 2007 – 2011

The Brighter Futures project (Mental Health Foundation, 2011a) worked across three areas in Scotland to pilot a peer mentoring approach for isolated older people. It was led by the MHF in partnership with GAMH (South Glasgow), RAMH (East Renfrewshire) and Seniors Together (South Lanarkshire). The aim of Brighter Futures project was to work with older people to deliver a peer mentoring service aimed at improving the wellbeing and the quality of lives of more isolated older people through enhancing their social networks and enabling meaningful community engagement through, for example, universities, arts groups, exercise classes and faith community groups.

Improvements in mental health and wellbeing were identified as key benefits of the project for the participants. Before the project all participants interviewed had described feeling very lonely. All had lost contact with most of their social networks, and participants consistently described feeling very low in mood with little hope for the future. After nine months of engagement with the project, improvements in self-esteem were indicated for all participants, and improvements in perceived social isolation were indicated for 74% of the participants. The mentor was identified as one of the most important features of the project. They were seen to act as positive peer role models, and by sharing their own achievements and aspirations, were viewed as inspiring by participants. The participants felt that being supported by someone who had 'walked the talk' helped to motivate them to take risks and try new things. The project was also beneficial to the volunteers who became mentors.

Right Here, England and Northern Ireland, 2009 (ongoing)

The Right Here programme is a five year collaboration between the MHF and the Paul Hamlyn Foundation (Right Here 2012). The aim of the programme is to improve the wellbeing and mental health of young people aged 16 – 25 through the participation of this age group in developing new and innovative interventions in mental health.

Peer support is an integral part of each of the four Right Here projects (in County Fermanagh, Brighton and Hove, Newham and Sheffield) where young people are designing and delivering a wide range of targeted and general mental health support to their peers. Young people are also being trained as peer

researchers, to enable them to have a stake in the overall evaluation of the projects that is being undertaken by the Tavistock Institute.

One example of the peer support involved in Right Here is that of the two community-based peer educators who are on long term placements in small community organisations for Right Here Fermanagh. The most recent evaluation of the Right Here projects noted that Fermanagh's peer mentoring approach had been particularly effective in providing a link with young people in rurally isolated areas who might not otherwise have been in contact with community services. It also highlighted the importance of the peer educators in providing positive role models for the young men and women they come into contact with.

Exploring peer support as an approach to supporting self-management, Scotland, 2010-2011

In January 2010, the Scottish Development Centre for Mental Health (SDC) was awarded funding from the Long Term Conditions Alliance Scotland (LTCAS) Self Management Fund to develop a feasibility study. In February 2011, the SDC merged with the Mental Health Foundation and the feasibility study became part of the Foundation's work programme.

The study aimed to explore peer support as an approach to support self management and to assess the potential for formalised peer support to be developed for people with long term conditions (Mental Health Foundation, 2012). It found:

- those who participated demonstrated passionate support for the unique added benefits that peer support can bring to those living with long term conditions and the professionals who support them
- peer support is often provided by people who have a similar condition to those they are supporting. However there is support for the idea of a 'generic' peer worker who embodies many of the wide range of other key factors that contribute to being a successful peer (e.g. ability to empathise and listen)
- there is a range of ways to deliver peer support to people with long term conditions, from peer mentoring to professionally facilitated peer support. However access to peer support is still limited and patchy
- key challenges need to be overcome, including raising awareness about the benefits of peer support and improving

access to it; developing better levels of integration between the statutory and voluntary sector in providing peer support; and developing some standards that provide guidance and support to those employing volunteer or paid peer support workers and a standard training for peer support workers.

Developing Peer Support for Long Term Conditions, Lothian and Lanarkshire, 2011-2012

The Mental Health Foundation, in partnership with NHS Lanarkshire, NHS Lothian, British Heart Foundation, Chest Heart & Stroke Scotland, Diabetes UK Scotland, RCGP Scotland and Waverley Care is leading the Delivering Peer Support for Long Term Conditions project, funded by LTCAS, to take forward the recommendations from the feasibility study above. Project activities include:

- 'Peer Support - Making it Happen' - a free one day training course aimed at planners, commissioners and service leads to act as a primer for the development of peer support services for people with long term conditions
- 'Peer Support – Principles in Practice' – a free two day training course aimed at current and prospective providers of peer support services to enhance the quality of support received
- two nationwide networking events
- peer support guidance to assist with the development and delivery of peer support services
- an online information resource.

Learning for Life, Northamptonshire, 2008 – 2011

Learning for Life was a learning on prescription programme that offered adult learning courses for people experiencing mild to moderate depression and anxiety in Northamptonshire (Mental Health Foundation, 2011b). It was provided by Northamptonshire Teaching Primary Care Trust and Northampton County Council Adult Learning Service and evaluated by the Foundation over three years.

The evaluation found that the elements of peer support the programme provided contributed to the success of the learning courses in improving participants' mental health. Many of the tutors had themselves experienced mental health problems in the past, and saw this as the reason why they were attracted to the project. People found it helpful when tutors shared their own personal experiences of mental health problems

and the ways in which they learnt to manage them. This built trust between the tutor and the students, helping people to be more open and honest about their experiences and more likely to listen to what the tutor had to say. Some learners drew inspiration from their tutor's own experiences, seeing them as a role model for how they might manage and recover from their own mental health problems.

The project also enabled learners to provide informal peer support to one another, helping individuals to feel less isolated. Some learners remained in contact with others from their course, and continued to be supported by them after the courses had finished.

Self-management for people with a severe psychiatric diagnosis, Wales, 2009-2012

The project was funded by the Big Lottery Fund Cymru. The Foundation worked in partnership with MDF, the Bipolar Organisation and Cardiff University on the first initiative of its kind in the UK.

The Foundation developed and delivered self-management and peer support, recruiting service user trainers from across Wales, and people who attended the self-management courses, to become peer support group mentors. The Foundation trained over six hundred people and developed peer support groups across the country. The group members support each other to set goals and overcome the problems that make achieving those goals more difficult. The intervention is currently being evaluated.

Similar initiatives are being developed for people in prisons and single parents (Wales), and young Black men, women, and people in supported housing (England).

Dementia Engagement and Empowerment Project (DEEP), UK, 2011/12 (ongoing)

The Dementia Engagement and Empowerment Project (DEEP) is a project led by the MHF in collaboration with Innovation in Dementia and the Alzheimer's Society, funded by the Joseph Rowntree Foundation. The project aims to identify and map out groups, projects and activities across the UK that are led by people diagnosed with dementia to influence the services and policies that affect them.

MHF completed a survey of different dementia initiatives and received responses from over 80 groups involving people living with dementia. The survey revealed that peer support and more informal social activities are important at two levels: where members are looking for

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support to cope with the impact that dementia is having on their lives personally; and to provide support to members who are involved in awareness raising and influencing activities. A full report is due to be published later in 2012.

Self help for people with dementia, London, 2012-14

In collaboration with a Housing 21, a social housing provider, the Foundation has secured funding to set up, run and evaluate facilitated self help, peer support groups for people in early stages of dementia and their partners living in extra care and sheltered housing schemes in London. The aim of the project is to find out if these groups enable people to live independently for longer, improve their quality of life and reduce social isolation. It is a two year project that started in February 2012.

MyCare, England, Scotland, Wales, 2009 - 2010

This project, carried out in collaboration with the Princess Royal Trust for Carers, looked at the experiences and needs of young people aged 9 – 25 years old who are looking after parents with severe mental health needs (Mental Health Foundation, 2010).

The study was particularly interested in service provision for young carers, how they learnt to best cope with their situation, and the strategies they used to do so. The findings showed that, among other things, young carers wanted someone to talk to, who would listen and not judge them. One of the report's recommendations for the improvement of young carers' services was to encourage young carers of parents with mental illness 'to meet with other young carers who may have a similar situation, either within the young carers' service or with other nearby young carers' services' with the suggestion that this could be achieved through peer support sessions.

Work in learning disabilities

What about us? UK, 2005 - 2008

'What about us?' was an action research project carried out by Foundation for People with Learning Disabilities (FPLD) - part of the Mental Health Foundation - to promote the emotional wellbeing of young people with learning disabilities in inclusive secondary schools and colleges (Foundation for People with Learning Disabilities, 2008). It involved

students attending nine schools and colleges across the UK. The project reviewed the impact of inclusion on the emotional wellbeing and personal and social development of young people with learning disabilities, and went on to develop strategies for overcoming barriers to inclusion suggested by young people.

One of the key findings of the project was that young people with learning difficulties, disabilities and/or special educational needs welcomed support from peers and regarded schemes that promote support between students as especially valuable. 'Buddy' systems were found to be one effective way in which peers could provide support, making the transition to a new school or college easier for young people with learning difficulties. This sharing of experience helped the school students feel happier and more relaxed about going to college, as they could see that their college friends had 'survived' the transition.

Mind the Gap, Somerset, 2002 - 2004

Mind the Gap was an action research project that aimed to improve the emotional and mental health support for young people with learning disabilities as they move into adulthood. It was carried out by the Norah Fry Research Centre, Bristol, in partnership with those involved in service provision for people with learning disabilities in Somerset.

The project's outcomes included a peer support course facilitated by young people themselves, The Strongest Link. This focussed on the emotional support that would provide other young people with opportunities to develop self-advocacy skills, their ability to take the initiative, and to become responsible members of society (Foundation for People with Learning Disabilities, 2005). The young people spoke of the sense of achievement they felt in running the course, and in seeing it go successfully. The course enabled the young people involved to talk more openly and fluently about their emotional needs and feelings, and also provided an opportunity to meet new friends and become part of a team.

Another part of the project included parents developing and facilitating support courses for other parents as a way of developing emotional resilience and easing the stress of caring. The parents developed a course called Our Link to the Future, which provided a forum for parents to mutually support one another emotionally and practically. The course included sessions on communication, managing stress, assertiveness and behavioural management, but also more relaxed group sessions such as going for a

picnic. This project provided an opportunity for the parents to share their feelings, vent their emotions and exchange coping strategies. The evaluations during and after the course showed that the most appreciated aspect of the course was the opportunity to meet other people in the same position as themselves.

Valuing Families, Kent, 2010-12

Valuing Families in Kent was a project to build the leadership skills of family carers and to give families a greater voice in the development of opportunities and delivery of support to young people and adults with learning disabilities.

The work led to the development of a booklet that came out of the experience of one of the families who had been supporting their daughter to leave home to live in her own flat and who had encountered many problems (Foundation for People with Learning Disabilities, 2011). As the family put it, “We have learnt the hard way and now want to share our experiences”. The booklet demonstrates how families can learn from each other, their peers, about how to improve the quality of support available to people with learning disabilities through direct payments and personal budgets. The booklet is currently being adapted for a national audience.

Learning for Leadership, 2006 (ongoing)

Learning for Leadership, and Learning for Leadership at Transition, are development programmes for people with learning disabilities. They aim to support participants to understand the rights of disabled people, gain knowledge about rights and responsibilities, understand the concepts of empowerment and leadership and acquire the belief that they can make change happen for themselves and others.

A key element of the Learning for Leadership at Transition project was that it involved a young person with learning disabilities as a co-facilitator of the sessions. The project worked with a young man who was registered blind who was able to speak about his experiences of gaining his independence and the importance of person centred planning in a way that was in touch with the young people taking the course. Using a young co-facilitator was found to be particularly successful because he could provide a peer role model for those taking the course.

Conclusions and recommendations

Both the published literature on peer support and the findings from the Foundation’s work programme (illustrated by participants’ comments at Annex A) demonstrate that, in its various forms, peer support has widespread benefits for people with mental health problems, people with dementia and people with learning disabilities. The mutual support that peers offer improves the wellbeing of both the person receiving the support and the person giving it, increasing confidence and empowering people to take control of their lives.

There are a number of models of peer support. Informal arrangements, where individuals may simply offer peer support spontaneously or on an ad-hoc basis, can clearly be useful, and have the advantage of being very flexible. There may be times, however, when the support offered is not necessarily what the recipient wants – effective peer support must be based on mutual agreement.

More formal support may be arranged through local organisations from the statutory, independent and voluntary sectors. Peer support workers may still contribute on a voluntary basis, or alternatively (and increasingly) they may look to become paid members of a mental health or learning disability support team. These arrangements require formal training and monitoring procedures, and agreed procedures between the peer support worker and the recipient of the support. However for this to happen commissioners and providers of services, including frontline health and social care professionals, need to understand the principles and practice of peer support themselves.

The Foundation believes that the evidence of the effectiveness of peer support (in terms of improved recovery, quality of life, reduction of pressure on services and cost effectiveness) has been clearly demonstrated.

As a result, we recommend that:

- mental health services create environments that allow and encourage opportunities for the development of informal peer support between service users
- organisations responsible for undertaking local needs assessments, and for planning and commissioning local mental health support across the UK, should ensure that accessible formal peer support is built into their plans and is widely available to all who experience mental health problems, including dementia, or who have a learning disability
- in designing local peer support, planners, commissioners and providers of mental health and learning disability services should take into account the views of people who use services and their carers
- all health and social care professionals supporting people with mental health problems, including dementia, and people with learning disabilities should inform them about local peer support schemes, and opportunities for people to become peer supporters themselves
- peer support services should be encouraged and supported to implement robust evaluations of their services to ensure continual quality improvement; strengthen their case for continued funding; and add to the wider evidence base on peer support
- where resources are limited, mental health peer support should be targeted at those with mental health needs who are most excluded and disadvantaged in society, and who encounter most barriers to receiving mental health care and treatment
- all formal peer supporters, whether voluntary or paid, must receive appropriate levels of training and support in order to carry out their role effectively and safely
- commissioning bodies across the UK should publish information on local peer support services so that a map of provision is available to people who use services, their families and health and social care professionals
- commissioning bodies across the UK, liaising with statutory, voluntary and independent sector peer support providers, should conduct an annual audit of peer support services in their local area to assess their availability, scope and effectiveness.

ANNEX A

Personal experiences of peer support

The comments below are from participants across a range of the Foundation's peer support work. They also include personal experiences of peer support submitted in May 2012 by members of the Foundation's Policy Panel, some 200 people including service users, carers and health and social care professionals.

What service users say

Improved mental health and wellbeing

- 'Yes absolutely my lifestyle is totally normal now. I don't have any problems going out and I have lots of friends again...I've made it – it's been totally positive no negative outcomes.' [Brighter Futures](#)
- 'I get out a fair bit now. Not depressed any more, on Wednesdays I call the dial a bus and go into town. It was Sheila [Brighter Futures Co-Ordinator] that organised that for me the first time and now I have the number and call myself.' [Brighter Futures](#)
- 'I have given quite a lot of peer support in my time especially to a close friend who went through two nasty divorces and is now really enjoying her life once again. I twice suffered from depression, once was post-natal and the other, which I found worse, was after my mother, who I had been caring for to the best of my ability as well as having a full-time job and two teenage boys, died... I carried on throughout this year-long depression which was very hard. During that time I talked to one of my friends who had suffered in the same way as I did and that was invaluable. I found it better to stick to one person and we made it into a weekly meeting. She was someone I could ring at any time and I did the same for her later. We had a lot of laughs as well as problems.' [Policy Panel](#)
- 'I was flying on broken wings and it was a small group of service users at [named] Hospital who pulled me through over a seven year period. So, yes, I will always be eternally grateful to my friends who were on the case before peer support was ever mentioned.' [Policy Panel](#)

Improved social connectedness and social skills

- 'I was so used to being isolated and not able to go out that it wouldn't have happened without the support of a volunteer.' [Brighter Futures](#)
- 'It's changed quite a lot for me. Since I've been in Mind the Gap, I've met [3 names given] and got on perfectly about work. It's good to be part of a team. I'm often a bit of a loner'. [Mind the Gap \(The Strongest Link\)](#)
- 'There were chances to talk about personal things on the course, and this has helped me to open up to other friends now'. [Mind the Gap \(Our Link to the Future\)](#)

Empathy and understanding received from peer supporters

- 'The school students enjoyed meeting and being supported by familiar people at college – and the college students enjoyed being helpers.' [What About us?](#)
- 'Participants told us that they felt understood and that their mentors were often very supportive, patient and reliable'. [Brighter Futures](#)
- 'Having peer support is invaluable. You are talking to people who have had like for like or similar journeys to you so they have real empathy with you. They have time to spend with you and show a level of care that is sadly lacking within the health service. There are gems within the health service but they are all too rare. Also, peer support workers do not judge you and you feel more open to talking with them than healthcare professionals.' [Policy Panel](#)
- 'My main experience of peer support was during my time in psychiatric hospital. It was on these occasions when I met people who were experiencing similar or the same symptoms. A crucial part of my time there was spent discussing shared symptoms and experiences. I felt that as some of the experiences of mental health symptoms are so unique, it was a real relief to be able to relate, share and laugh about some of these things. In fact, I think it could be something that is offered via a more structured service – a kind of peer group 'meet up.' For me, it relieved the pressure of feeling like I was alone with my illness, or abnormal – to realise that

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someone other than myself was going through the same thing was a vital part of my understanding of the illness. I also felt more comfortable telling people I met with the same or similar illness my experiences, because I was afraid of judgment or misunderstanding with other peers who were well. I have remained in contact with one particular friend from hospital and aside from a normal course of friendship, we do encourage each other to keep going, restart medication if necessary, complain about things and generally gee each other on. I think, for me, this has been crucial.'

[Policy Panel](#)

- 'I am currently feeling quite stable in my mental health, but if (when?) I were to have another blip, I would turn to peer support with more faith and trust than mental health services.' [Policy Panel](#)
- 'I have friends who have experienced services and mental distress and I can be completely honest with them. I think these friends understand the legacy of long term distress and use of services. It feels we have a connection which I cannot find in my workplace or community life.' [Policy Panel](#)
- 'What amazing peer support they have given me [via Facebook]. "Saving my life" for sure. They trusted me to work on their poetry section transforming the poems in a way they reach out to the reader. Now that's what I call Mutual Peer Support. And there is a lady in a disability group giving me several days of such valuable info around painkillers. Mutual help and support with many others chipping in. It's the wonderful people on Facebook giving Peer Support on a World Wide Scale.' [Policy Panel](#)

Providing hope and encouragement

- 'The tutor has been through it, it allows you to open up more, you don't get judged. When you see other professionals it's like 'I'll trust you, you're the expert, but you don't know what you're talking about, you've not been through this.' I found it inspiring – if they can do it, I can do it.' [Learning for Life](#)
- 'The young people from the college were the 'experienced' buddies – they remembered what it was like to be new in college and how anxious they had felt and this helped the visitors feel happier and more relaxed about going to college. They could see that their college friends had 'survived' being new.' [What about us?](#)

- 'There is something very different about support provided by peers as opposed to that provided by people who work in professional roles in the NHS or voluntary providers. The willingness to disclose their own experience encourages hope that recovery is achievable. Their lack of judgement and time to listen mean that my own experiences have felt valid and valued. And their local knowledge and expertise have helped to direct me towards opportunities I hadn't considered. Peers have also helped me to realise that I have learnt from my own experiences and have knowledge, skills and experience to share for others. I have felt accepted and skilled - something that statutory mental health services have never offered.' [Policy Panel](#)

Increased confidence

- 'I have felt changes. I feel more confident. When I started... I was sort of shy and embarrassed. But I can look into a camera straight now, like I'm looking at you. I can do a lot more things, and I am more confident about myself. Yes, I feel more confident than I ever have.' [Mind the Gap \(The Strongest Link\)](#)
- 'I have found the interaction with other members of the [peer support] group extremely comforting and inspiring, not to mention confidence boosting at times. I now feel less isolated, more hopeful, more supported (particularly during difficult times), and more understood. All of this has had a positive impact on my esteem and confidence. Being part of this group, has actually reminded me of some strong personal qualities I have inside me to lead and motivate others. I think it is extremely important to have this service available. It makes a real difference talking and sharing with people who understand first-hand the issues and challenges faced by mental ill health.' [Policy Panel](#)

What peer supporters say

Feeling like a valued worker and contributing citizen

- 'Volunteers felt that they were contributing positively to society and had a role that was valued' .[Brighter Futures](#)
- 'I qualified as a Person-Centred Counsellor last year, and it has helped (without exception) every client I've had who's asked me if I've ever been depressed... when I disclose to them that I have. It's like they

realize I've actually been there and know what it feels like. It also gives them hope that they can feel better.' [Policy Panel](#)

Being able to 'give something back'

- 'I think my own reasons for getting involved were that I had been badly depressed myself in the past and suffered from work related stress as well and have found ways to manage my own stress and felt that the skills I had learnt could be shared with other people.' [Learning for Life](#)
- 'I had a mental health breakdown myself and really didn't know what I wanted to do... when I was introduced to Brighter Futures I thought that sounds good, as I thought I want to pay something back.' [Brighter Futures](#)
- 'To be able to touch on my own experience, you know, be a bit of an advocate as somebody who has gone through difficult times but come through the other end'. [Learning for Life](#)

Provides skills and employment benefits

- 'I work shifts now as I have got a new job in the care industry. Because of being in Brighter Futures I got a job working with vulnerable people, mostly elderly. Being a volunteer prompted me to look at that side of work. Because of my experience working with people with mental health issues, I felt I could do it and I love it – it's been so positive for me.' [Brighter Futures](#)

Increased levels of self-esteem and hope for the future

- 'How have I found my experience as a mentor – well just simply I would have to say without a doubt that it's given me a much Brighter Future'. [Brighter Futures](#)
- 'Those people who have used either the peer support service run by the charity or by the NHS Trust here in [English city] have found it of great help. They are seen as a person rather than as a patient with a diagnosis. Particularly beneficial has been the hope engendered by seeing people who have been hospitalised with psychosis doing well and in work and also being able to talk with someone who really knows what you are going through as they have experienced similar things. We also find that the activities that are organised by the peer support workers are things that

the young people really want to do.' [Policy Panel](#)

Difficulties encountered

Despite the obvious benefits cited by individuals, some also spoke of the difficulties encountered in establishing, maintaining and using peer support.

- 'Setting up the charity offering peer support was hard work but worthwhile. Employing staff is always demanding. Training is hard to come by and supervision. NHS is not too good at referring to external organisations and some staff are suspicious and think they are too radical. Very limited service offered locally either by small charity or the NHS which has very few peer support workers. My son has never had the opportunity to have a peer support worker.' [Policy Panel](#)
- 'It has been difficult at times to keep things going, partly because there were only a limited number of organised sessions. Since these finished, it has been down to individuals to keep up contact via email and arrange things to do. It could do with more structured leadership at times. This is mostly a funding issue I think.' [Policy Panel](#)
- 'We have developed peer support in local, unfunded, voluntary groups. It has been very difficult to maintain continuity. How to support volunteers? How to offer volunteers a sustainable opportunity which values growing expertise? Without an organisation to support it, it turns into befriending. There is also the danger that peers are not aware of adventurous possibilities in stretching the idea of recovery to thriving and a life beyond illness.' [Policy Panel](#)
- 'I think that peer support in services can have its agenda set by [mental health] Trusts and again focus on brief recovery groups and initiatives rather than the more involved support people may need but are now denied as a matter of course. I avoid group therapy because I picked up worse self-harming behaviours in the past from being with and observing others in crisis. I refused to enter a therapeutic community even though this involves a strong element of peer support I knew it would drag me down. Last year I decided that I needed to move away from mental health and would not choose to be a peer worker as there would be too many reminders. The assumption that if you have had problems you should work in MH services is unhelpful.' [Policy Panel](#)

Peer support in mental health and learning disability

- 'Peer support is different from professional as you are more equal and there is an honesty. This doesn't mean that I would want all helping relationships to be by peers. I would worry if the peer was in a bad place and unsupported at work as they could become ill again. I do find that some settings are less suitable for peer support - eg when I was treated for anorexia the peer support wasn't real. Others with this illness wanted me to put on weight and would say well done while avoiding this for themselves. There was competition to be the most ill.' [Policy Panel](#)

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The Mental Health Foundation is a UK-wide charity that carries out research, campaigns for better mental health services, and works to raise awareness of all mental health issues to help us all lead mentally healthier lives.

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