Describing a principles-based approach to developing and evaluating peer worker roles as peer support moves into mainstream mental health services

Steve Gillard, Rhiannon Foster, Sarah Gibson, Lucy Goldsmith, Jacqueline Marks and Sarah White

Abstract

Purpose – *Peer support is increasingly being introduced into mainstream mental health services internationally. The distinctiveness of peer support, compared to other mental health support, has been linked to values underpinning peer support. Evidence suggests that there are challenges to maintaining those values in the context of highly standardised organisational environments. The purpose of this paper is to describe a "principles-based" approach to developing and evaluating a new peer worker role in mental health services.*

Design/methodology/approach – *A set of peer support values was generated through systematic review of research about one-to-one peer support, and a second set produced by a UK National Expert Panel of people sharing, leading or researching peer support from a lived experience perspective. Value sets were integrated by the research team – including researchers working from a lived experience perspective – to produce a principles framework for developing and evaluating new peer worker roles.*

Findings – *Five principles referred in detail to: relationships based on shared lived experience; reciprocity and mutuality; validating experiential knowledge; leadership, choice and control; discovering strengths and making connections. Supporting the diversity of lived experience that people bring to peer support applied across principles.*

Research limitations/implications – *The principles framework underpinned development of a handbook for a new peer worker role, and informed a fidelity index designed to measure the extent to which peer support values are maintained in practice. Given the diversity of peer support, the authors caution against prescriptive frameworks that might "codify" peer support and note that lived experience should be central to shaping and leading evaluation of peer support.*

Originality/value – *This paper adds to the literature on peer support in mental health by describing a systematic approach to understanding how principles and values underpin peer worker roles in the context of mental health services. This paper informs an innovative, principles-based approach to developing a handbook and fidelity index for a randomised controlled trial. Lived experiences of mental distress brought to the research by members of the research team and the expert advisors shaped the way this research was undertaken.*

Keywords *Mental health services, Lived experience, Peer support, Experiential knowledge, Fidelity, Randomized controlled trials*

Paper type *Research paper*

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Background

An established sociological literature on role change in the workforce suggests that there are innovation and early implementation stages at which system-wide role adoption remains in doubt (Bernard, 1976). The introduction of peer workers into mental health services as an organised approach to providing mental health care – in the UK and many other countries – seems to be past those tenuous early stages. Arguably, in the UK at least, we are beyond the

so called "tipping point" whereby a new role becomes generally accepted as a fixture in the workforce (Turner, 1990). Most National Health Service (NHS) Mental Health Trusts and large not-for-profit mental health care providers in the UK now employ at least some peer workers in an ever wider range of service delivery contexts. Strategy and commissioning guidance internationally are actively encouraging the development and introduction of peer workers into mental health services (e.g. JCPMH, 2012a, b; MHC Canada, 2012; MHC New Zealand, 2012; NICE, 2016), while funding arrangements in the USA and Australia provide a powerful incentive where eligibility of peer support services for state funding is linked to nationally accredited training (Kaufman *et al.*, 2012; ISC, 2013). However, the sociological literature referred to above tells us that role adoption, in itself, is not a guarantee of sustainability of a role as it was originally envisaged; that there are ongoing risks to the distinctiveness of a new role if favourable conditions are not met (Turner, 1990). Just because mental health care organisations employ people called peer workers, it does not inevitably follow that those workers continue to provide support in a way that is different from the support provided by other mental health workers. The aim of this paper is to explore the challenge of ensuring the distinctiveness of peer support as peer worker roles are mainstreamed into mental health services.

There is a strong argument that the distinctiveness of peer support is attributable to a values base that has its origins in the naturally occurring, real-world interactions between people supporting each other with their emotional distress (Mead and MacNeil, 2006), a long way from the formal delivery of mental health services. Indeed for many people peer support exists as something very separate from, or even in resistance to mental health services where a set of medically defined, expert-to-patient values prevail that are anathema to the authentic peer support relationship (Faulkner and Bassett, 2012). Attempts have been made to define value sets that underpin peer support. For example, O'Hagan *et al.* (2009) identify three primary values: equal power relationships – a commitment to consumer/survivor choice and control over peer support at individual and organisational levels; identification with each other – a sense of mutuality, camaraderie and acceptance between peers, reciprocal roles of helping and learning, and minimal distinction between "staff and clients"; holistic understanding of madness – emphasising the whole of life, strengths rather than illness focussed, and confirming the validity of personal experience.

It has been suggested that when peer support is intentionally provided, in any context, there is work to be done to maintain those values (Mead *et al.*, 2001; O'Hagan *et al.*, 2009). There is an additional challenge when this takes place within a highly standardised organisational culture (Stewart *et al.*, 2008) such as the NHS. Furthermore, it has been questioned whether the values that "make peer support different" can survive in mental health services at all if a peer-led ethos is not also retained (Faulkner and Kalathil, 2012). In attempting to address this challenge, some organisational initiatives have been at pains to articulate the values base underpinning the peer support. For example, US-based Intentional Peer Support offers itself as "unique from traditional human services" through its partnership approach (both parties are "invited to learn and grow", rather than one helping the other), its creative rather than problem-based approach and its focus on relationship and community rather than individual change alone (Mead and Filson, 2017). In New Zealand, the delivery of some state-funded peer support has been shaped by Maori understandings of connection and relationship grounded in "things that are intrinsically shared" between people (Scott *et al.*, 2011).

It is interesting to note that, while there are numerous qualitative and observational studies that attest to the benefits of peer support (Repper and Carter, 2011), more formal research (randomised controlled trials and systematic reviews) do not indicate improved outcomes when peer support is compared to other forms of mental health support (Pitt *et al.*, 2013; Lloyd-Evans *et al.*, 2014). Arguably trials are not measuring the outcomes that people experience as benefits of peer support – for example, a trial might focus on service delivery and productivity outcomes – and so benefits experienced by participants go largely unmeasured. However, where trials have attempted to measure and compare experiential outcomes (e.g. empowerment: Ochocka *et al.*, 2006; Rogers *et al.*, 2007) significant differences are not shown. Additionally, it is noted that trial methodology – especially the random allocation of people to receive peer support or not – can undermine the relationship at the heart of peer support (Corrigan and Salzer, 2003). To date,

only a single cluster randomised controlled trial has been reported, comparing veterans' mental health services including peer workers as part of the staff team with those without (Chinman *et al.*, 2015). This study showed a greater improvement in patient activation – measuring, for example, the extent to which patients know what their medication is for (Green *et al.*, 2010) – in those services with peer workers compared to those without. Authors note that it was difficult to attribute that difference to the peer component, with peers performing the same duties as other members of the team (Chinman *et al.*, 2015). The reviews cited above also note a lack of reporting of what peers do, how that is distinctive from what other mental health workers do and how that might bring about change (Pitt *et al.*, 2013; Lloyd-Evans *et al.*, 2014). It is possible that these studies are telling us that not enough attention is being paid to what peers are expected to do in their work, and therefore whether it is peer support that is being delivered and evaluated.

Challenges to offering values-based peer support in mental health services

Existing research is indicative of a number of challenges to delivering values-based peer support in formal mental health services, especially where this takes the form of one-to-one peer worker roles:

1. Simply employing someone, as a member of staff, to a peer worker role –a badge and a job title – can create difference and power imbalance in the peer-to-peer relationship (Gillard *et al.*, 2014). The word "peer" in the job title necessarily discloses that an individual has used mental health services and/or experienced mental distress. While this makes a strong statement about the validity of lived experience, it also removes choice and control from the individual (Moran *et al.*, 2013; Dyble *et al.*, 2014) and as such can act as a barrier to taking on the role.
2. Providing a standardised peer support training has the potential to formalise, or professionalise peer support (Faulkner and Bassett, 2012), and the "conundrum" of being ask to "work and train at being authentic" has been noted (Scott, 2011). Mandating peers to "tell their recovery story" as a way of delivering "recovery focused care" arguably conflicts with the relationship building process while imposing an understanding of mental health on an individual that might not chime with their own lived experience. The authors found that, in delivering their own largely self-directed, experience-based peer support training, trainee peer workers nonetheless began adopting some of the language used in the training, perhaps to demonstrate that they had "learnt well" on the course.
3. Inflexibilities in organisational cultures impose constraints on peer worker roles, even where the values of peer support are supported throughout the organisation. Scott and Doughty (2012) noted tensions – in some state-funded services in New Zealand – between the collaborative values underpinning peer support and the clinical need for auditable notes that could be accessed by the wider staff team.
4. There is an inherent tension in allocating people to peer support based on perceived clinical need, in comparison to the choice and control that people ordinarily exercise in forming relationships in the world outside of mental health services (O'Hagan *et al.*, 2009).
5. A lack of shared expectation about the peer worker role – especially in how lived experience is used – can result in peers feeling unsupported in using their lived experience, potentially eroding peer support values and defaulting to a generic support worker role (Gillard *et al.*, 2015). It has been noted in the sociological literature cited above that if workers in a new role are not enabled to bring a distinctive knowledge set to their work then the added value of their work is lost (Turner, 1990).

Peer support roles are now being introduced into a wide variety of mental health service settings, including specialist mental health services, with peer workers being ascribed a range of functions. In addition to the challenges listed above, it does not necessarily follow that the aims, function, training and so on that might apply to peer support in general adult mental health services are equally helpful as an approach to peer support in, for example, forensic mental health services (Shaw, 2014). In addition, there are cultural and identity contexts where, due to language

differences or stigma related to explicitly labelling services as "mental health", peer support is offered without being named as such (e.g. people working from an experiential perspective might simply be referred to as a "project worker"). While the service or project might be designed to support people with their mental health, people meet on the basis of a group activity (e.g. cooking, walking or making music), or a shared life experience (e.g. social isolation, parenting or being an asylum seeker) or identity (e.g. ethnicity or sexual identity). Defining who is a peer to whom in such settings, and what form peer support might take, is not something that can necessarily be transplanted from a statutory mental health care setting into the community sector (Kalathil, 2009; Gillard *et al.*, 2014).

Principles in reflective practice and the evaluation of peer support

All this raises an important question: if peer workers are going to be introduced into mainstream mental health services anyway, irrespective of whether we think that is desirable or not, is it not morally important to somehow ensure that peer support is delivered in a way which is potentially as beneficial as possible for those involved (i.e. that it is a values-based, rather than nominal peer support that is being offered)? If there is a broad consensus that what is distinctive about peer support is embodied in a set of values, perhaps the answer lies in somehow monitoring or evaluating the extent to which those values survive into mainstream practice. This paper will explore this question in relation to some existing experiments, and a new project that sets out to integrate a principles-based approach into developing and evaluating peer support.

In the USA, a fidelity measure was developed as part of an evaluation of eight consumer-led mental health services. While the structure and aims for the projects were very different, a high degree of shared philosophy was noted. A fidelity measure was developed to explore the relationship between "common ingredients" of projects and outcomes, and to inform funding and development of future projects (Johnsen *et al.*, 2005). In Denmark, the National Social Services Department, in a programme to introduce peer support into mental health services through health, social care and grassroots partnerships, first developed a values framework through an extensive consultation process with stakeholders to the programme. The framework was used to guide the development of local models of peer support in three pilot regions, and as a basis for reflective learning prior to national roll out of the programme (http://socialstyrelsen.dk/projekter-og-initiativer/handicap/peer-stotte-initiativet). In the UK a large programme led by the not-for-profit organisations Mind, Bipolar UK and Depression Alliance supported the development of new grassroots peer support initiatives in nearly 50 community sector organisations. Evaluation of the programme worked with stakeholders to develop a "values and principles framework" for evaluating peer support projects. Mindful that peer support can mean different in different community contexts, the framework sought to articulate values and principles that might underpin all peer support, and those that are specific to particular communities or service delivery contexts. The framework was also developed as a "legacy tool" to support reflective learning and capacity building in peer support in community-sector projects (http://mcpin.org/evaluation-of-mind-peer-support-programme).

A principles-based approach to developing and evaluating a new peer worker role

A UK National Institute for Health Research-funded programme, ENRICH, seeks to develop, pilot and trial a new peer worker role supporting discharge from inpatient to community mental health care. In response to the challenges set out above, the ENRICH team developed a peer support principles framework. This framework was designed to inform development of both the ENRICH peer support for discharge handbook, and a principles-based fidelity index. The fidelity index was designed to assess the extent to which peer support values explain any differences in outcomes observed in the trial. In contrast to the frameworks referred to above, which were largely focussed at the service or group level, the ENRICH framework was specifically designed to inform the development and evaluation of one-to-one peer worker roles in mainstream mental health care.

Method

The development of the ENRICH peer support principles framework addressed a simple question:

> What are the principles that should inform the development and evaluation of one-to-one peer support in mental health services in order that the values underpinning the distinctiveness of peer support are maintained in practice?

The development process took place in three stages. First, a systematic review of one-to-one peer support in adult mental health services (reported elsewhere) extracted data from studies on the values and principles underpinning peer support. The review included reports of evaluations published outside of the peer-reviewed academic literature (the grey literature) as these were often produced by peer-led teams or organisations. This ensured that experiential knowledge informed development of the principles framework, alongside formal academic knowledge. It is interesting to note that a much higher proportion of data relating to principles and values came from the grey literature than did from the academic literature (12 of the 95 studies included in the review were from the grey literature). Data were coded – given succinct labels – and grouped into categories that were meaningfully similar (i.e. sets of similar principles). Those codes and categories are presented in Figure 1 with the principles identified from the grey literature highlighted, and frequencies indicated where individual codes appeared in more than one source in the data.

Second, a National Expert Panel (NEP) was convened of ten people all of who had lived experience of sharing peer support, developing and leading peer support projects in either the not-for-profit or statutory mental health sector, or of doing research about peer support from a lived experience perspective in the UK. In a first task each panel members was given five blank cards and asked, individually, to address the question above, noting one principle on each card. In the second task the panel were asked, together, to sort the cards into groups of meaningfully similar principles. Notes of the discussion were made whereby the panel clarified the meaning in each others' cards, gave reasons for groupings, and defined and labelled groups of principles. The output of the NEP is given in Figure 2.

Finally, the two sets of outputs were mapped onto each other and an iterative process of labelling a composite set of principles and producing a short definition for each principle was undertaken, circulating drafts between the team and, by e-mail, with the members of the NEP until the content was agreed on. Nearly half of the ENRICH research team bring explicit, lived experience of using mental health services and/or of mental distress to their work, either in their roles as researchers, peer workers or as leaders of peer support projects, ensuring that experiential knowledge shaped this process alongside academic and clinical expertise (Gillard *et al.*, 2012).

Results

The final version of the ENRICH peer support principles, stating that mental health services, training programmes, practice guidelines or interventions that are based on or include peer support should, in their development, delivery and evaluation, is as follows:

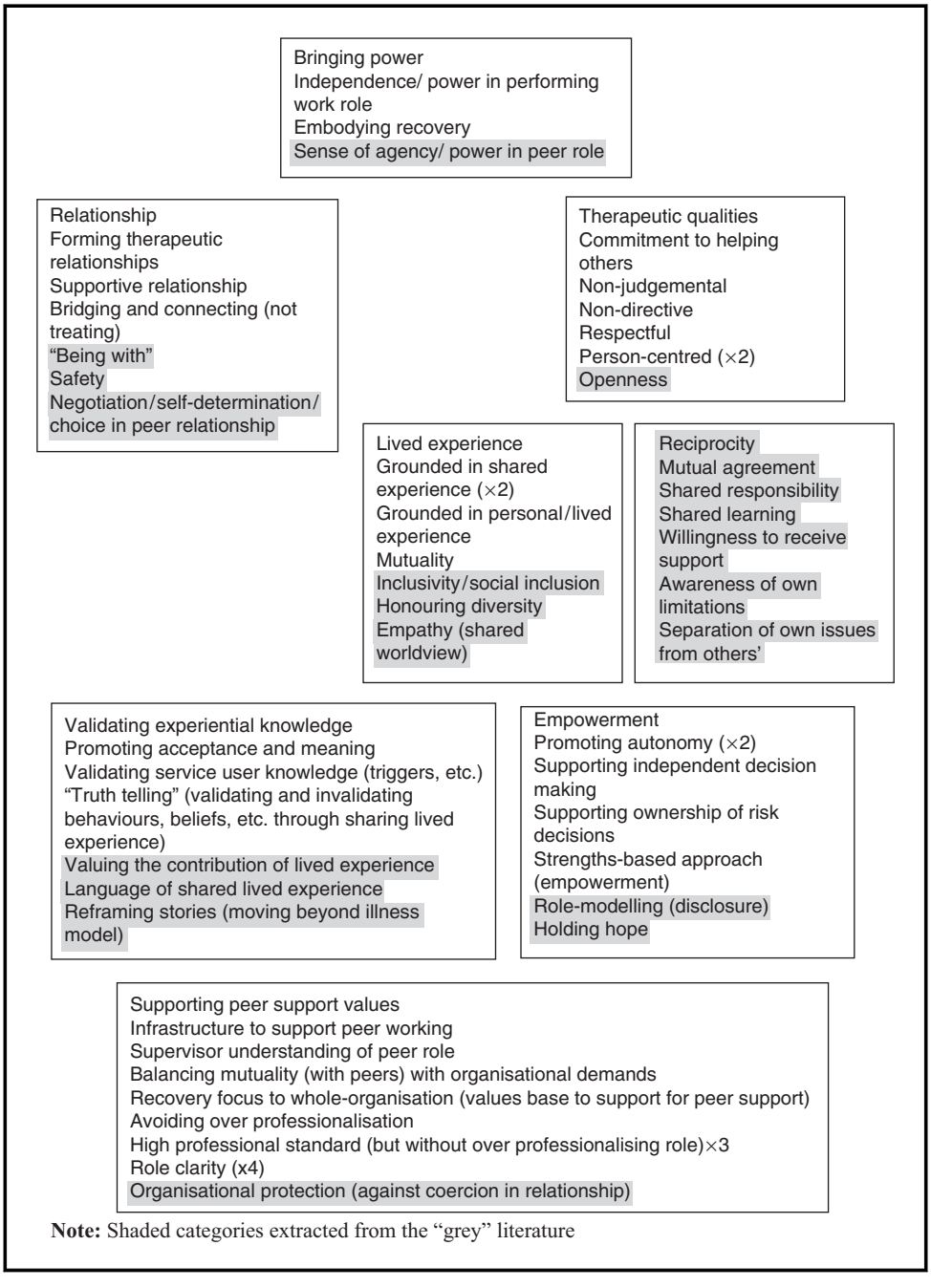
1. Support the building of safe and trusting relationships based on shared lived experience as fundamental to peer support:

   > Where that lived experience is appropriate to the service or community context in which peer support is given and received, reflecting and respecting the full diversity of lived experience that people bring.
   >
   > Through the offer of human kindness, compassion, time and space to share experiences of mental distress & difficulty and to build connections through shared language, learning and understanding.

2. Ensure that the values of mutuality and reciprocity underpin peer support relationships:

   > Mutuality in this context includes the qualities of empathy and mutual respect, a fundamental sense of equal value, and a connection to communities defined by the diversity of culture and experience.
   >
   > Reciprocity in this context includes willingness to both give and receive support, of listening and sharing, and of learning from difference.

Figure 1 Codes and categories of peer support principles extracted from the literature review



Note: Shaded categories extracted from the "grey" literature

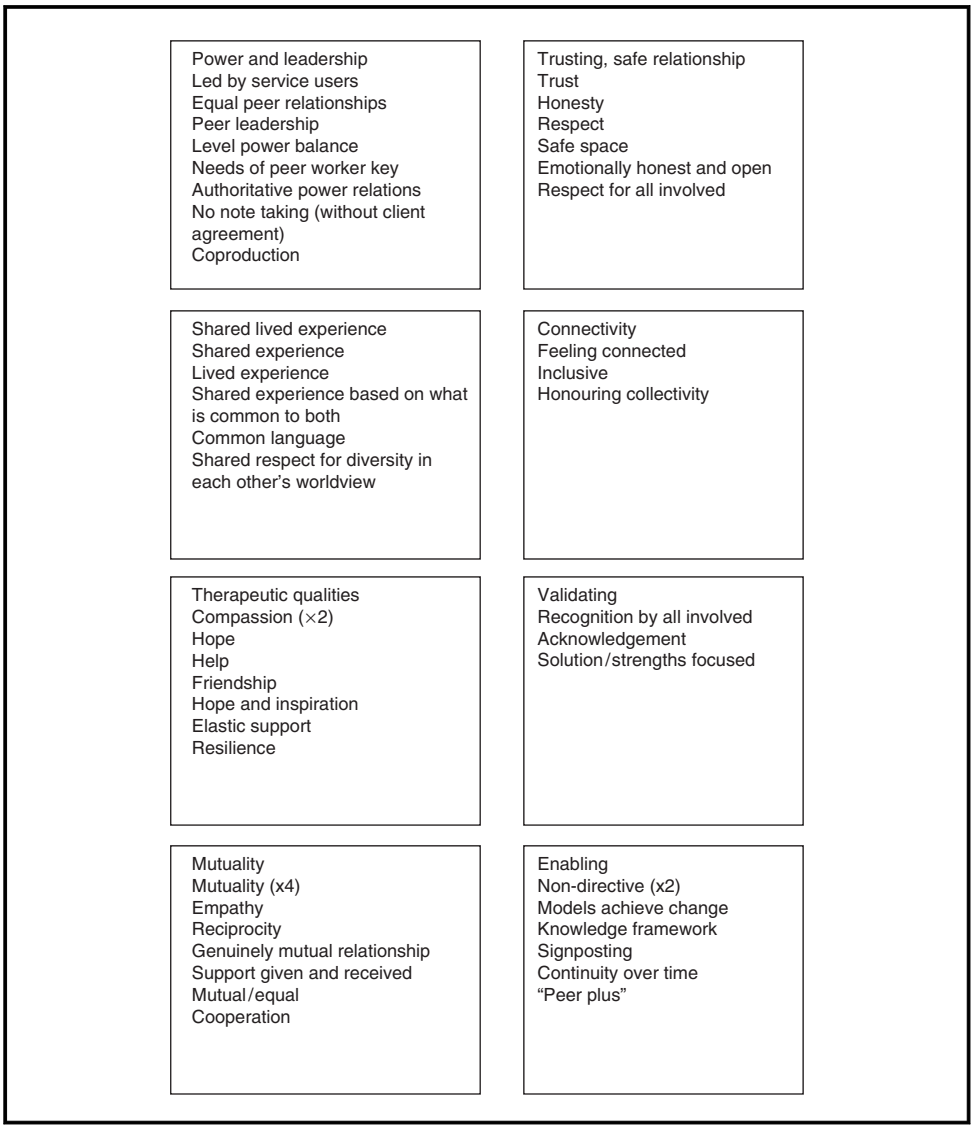
3. Promote the validation and application of experiential knowledge in the provision of peer support:

   Where validation means recognising, acknowledging and placing value on peers' personal lived experience as useful and powerful sources of knowledge and strength.

   Especially where that knowledge provides an alternative to, or complements other forms of knowledge about mental health (e.g. medical or psychological knowledge, recovery models etc.).

   Paying attention to the diversity of peers' lived experience as grounded in particular cultural contexts and ways of making sense and meaning.

Figure 2 Codes and categories of peer support principles generated by the national expert panel



4. Enable peers to exercise leadership, choice and control over the way in which peer support is given and received:

   To exercise leadership in peer support at an organisational level (especially where there are organisational constraints and control over how peer support is put into practice).

   To bring power to peer support roles within teams (enabling peers to use their lived experience in a safe and supported way).

   To retain choice and control over how lived experience is shared at an individual level and within relationships (including self-determination and negotiation in the sharing of lived experience).

5. Empower peers to discover and make use of their own strengths, and to build and strengthen connections to their peers and wider communities:

   To enable peers, in a non-directive, non-prescriptive way, to discover, develop and make use of their own strengths, skills and strategies, and to build and strengthen positive connections with their peers, networks and wider communities.

This principles framework is represented diagrammatically in Figure 3.

This framework has been used to inform development of the ENRICH peer support for discharge approach – the ENRICH handbook – in particular guiding the writing of the training that peer workers will receive, and the supervision and support they are offered at individual, team and organisational levels. Testing of the ENRICH principles-based fidelity index is currently underway, while in-depth qualitative interviews with peer workers, the people they support, their team leaders and the other staff they work alongside will also explore the extent to which the principles were reflected in the peer support in practice. It is envisaged that the framework and index will be useful in supporting the development and evaluation of other one-to-one peer worker roles in mental health services, while also going some way towards addressing those criticisms of existing trials that fail to properly describe and evaluate what might be distinctive about peer support (Pitt *et al.*, 2013).

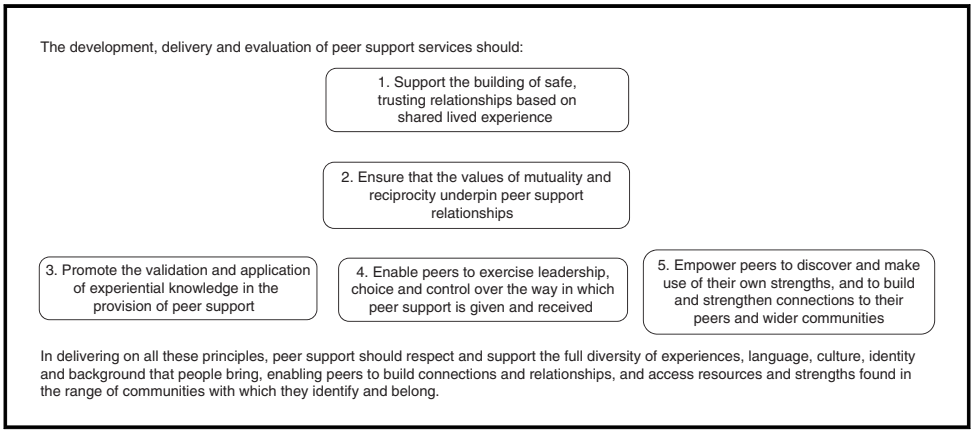
Conclusions

Reflection on the ENRICH project and those other experiments suggests that there is potential of a principles-based approach to reflect practice and evaluation to ensure that the distinctive values underpinning peer support are not eroded as peer support is mainstreamed into mental health services. Such an approach might take place in a number of stages:

1. There should be a clear understanding of the values underpinning any peer support project, including values that might apply more generally across different approaches to peer support, and values that are specific to a particular service delivery setting or local community.
2. There should be principles established that seek to protect those values as peer support is implemented into practice in mainstream mental health services.
3. Those principles should guide development and delivery of all aspects of implementation, from developing a role description, producing a training programme and providing supervision and support for peers at an individual, team and organisational level.
4. Peer support services should be evaluated and audited against those principles as a way of checking that the values underpinning peer support are being preserved and protected as peer support is implemented into practice.
5. Reflective learning, guidance and further development should follow evaluation to support the delivery of peer support that remains distinctive from other forms of mental health support.

The key learning from this paper is that commitment to reflective practice and evaluation of peer support is likely to play an important role in sustaining the values-based distinctiveness of peer support in a mental health service delivery context. Cycles of reflective learning should be

Figure 3 The ENRICH peer support principles



introduced to ensure that the values underpinning peer support are protected, i.e. peer workers are properly supported to use their experiential knowledge in the role. This reflective learning encompasses both formal evaluation (e.g. the use of principles-based fidelity measures) and the use of self-assessed organisational learning tools.

Given the wide diversity of approaches to peer support noted above – and that peer support can mean very different things to people in different service delivery and community contexts – it seems unlikely and probably undesirable that there is any one-size-fits-all set of values and principles underpinning all peer support. As such "off the shelf" approaches to peer support should be treated with some caution, except perhaps where these integrate flexibility for local peer and community expertise and knowledge to shape the peer support. Imposing a peer support "model", however carefully developed, risks sending a message that peer support is something to be learnt, rather than being grounded in the experiential knowledge of peers. A didactic approach to techniques – for example, a requirement to follow a prescriptive self-management manual – potentially sends a message that the codified knowledge in the manual takes priority over lived experience. Similarly, a formalised language of peer support might distance people for who mental health and peer support are understood and described differently – for example, in culturally specific contexts – possibly undermining the sense of mutuality and relationship building at the heart of peer support.

A final note of caution should be sounded. Given the centrality of lived experience to all value sets underpinning peer support, people working from a lived experience perspective should shape and lead this reflective learning process. Experiential knowledge must be central to research about peer support so that the academic and clinical assumptions embedded in conventional ways of doing mental health research do not constrain and reconstruct the evaluation of lived experience. Likewise, reflective self-assessment of peer support projects should not become a clinical or bureaucratic exercise. These should be inclusive, shared learning experiences, validating the experiential knowledge of people sharing peer support. Reflective practice and evaluation of peer support should not fall into the trap of codifying and regulating lived experience, and therefore imposing an orthodoxy or organisational constraint on what peer support can be as it moves into the mental health service mainstream.

Dedication

This paper and the ENRICH peer support principles are dedicated to the late Ruth Chandler. As a member of the ENRICH team Ruth chaired the meetings of our NEP we describe above, was a vital source of inspiration and leadership for the programme as a whole and will be hugely missed as a leading light in the UK mental health survivor movement.

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