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.

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In this time of scarcity, statutory mental health funding for independent self-organising community groups is limited. Those most likely to benefit might be labelled 'self help', 'peer support' or 'service user' groups which locate themselves alongside public authorities, helping them to meet their statutory requirements for community engagement or providing an alternative to statutory provision.

This article explores similarities and differences in the way the terms 'self help', 'peer support' and 'service user' groups are used in popular discourse. It notes the increasingly close relationship between self-organising groups and their statutory authorities and how this relationship may put at risk the benefits of the groups. Historical, cultural and social factors are discussed to help explain differences and separate developments within African, Caribbean and other Black communities (all referred to here as Black). Black groups are disproportionately represented within mental health services, and self organising groups play an important role in promoting wellbeing. For this reason, mental health funders are encouraged to recognise the potential of these groups and look within their local communities to find those groups promoting wellbeing for people most at risk of distress.

Self help groups:

There is no conclusive definition of self help groups; they emerge and develop in response to their social policy context (Borkman and Munn-Giddings, 2008). In the UK there has been little research on self help groups compared with the USA. However, the common characteristics identified by Self Help Nottingham - the only organisation set up in the UK specifically to support self help groups - are widely accepted and used by researchers. These include:

- members share a similar condition or life situation
- members come together to exchange information and strategies to address their problem
- sharing experiences enables the group to provide a unique quality of mutual support
- groups are run for and by their members.

People joining self help groups commonly experience immense relief on finding others in similar circumstances. As group members share their stories, they learn about the social factors which contribute to their situation and often come to understand it in a more positive light. Self help groups can be fun involving a range of educational, creative and social activities (Tyldesley and Phillips, 2009). Ownership and control lie with members, distinguishing self help groups from professionally managed support groups, but Chaudhary *et al,* (2010) note that many self help groups are supported in some way by practitioners, and the relationship is often complex.

There are some contradictions within the 'self help' label. Firstly, it implies that it is only about someone helping themselves. However, although new members may expect to benefit by receiving help or learning how to help themselves, it is through the giving of help to others that most of the benefit comes. Mutual support and reciprocity are the magical ingredients of self help groups. New members quickly find they can offer empathy, information and coping strategies to others and this makes them feel better (Clarke and Smith, 2003).

Secondly, because the focus of self help groups is on their shared condition or diagnosis, groups may seem inward-looking and apolitical, but members may turn to lobbying or delivering alternative services when a common cause of dissatisfaction emerges (Munn-Giddings and Borkman, 2005). In these two ways (and maybe others) they overlap with peer support and service user groups.

Peer support groups:

Less has been written on 'peer support groups', though in the mental health field there is a strong interest in peer support workers and services, where the benefits of the peer relationship are harnessed within statutory and voluntary sector workforces. It is this relationship that Dwight Reynolds eloquently describes in the article on the Canerows and Plaits Group elsewhere in this issue, and is defined here by Sherry Mead …

> '*It is about understanding another's situation empathetically through the shared experience of emotional and psychological pain. When people identify with others who they feel are "like them", they feel a connection. This connection, or affiliation, is a deep holistic understanding based on mutual experience where people are able to "be" with each other without the constraints of traditional (expert/patient) relationships.*'

(Mead *et al,* 2001:135)

The literature that does exist on peer support groups suggests they can share the four central features of self help groups identified by Self Help Nottingham. For instance, peer

support groups in Bradford were initiated and led by mental health service users who came together for sports, creative or faith activities, informally sharing their experiences with a strong ethos of mutual support (Seebohm *et al*, 2005). In peer support groups, the balanced involvement of paid practitioners remains a critical issue as it is with self help groups (Bignall *et al*, 2002). Academic discourse concerning self help groups might not distinguish peer support groups as a separate category, but in the community and in mental health services people are making different choices about the words they use. It may be that their preference has more to do with motivation, perception and culture than with group processes or features.

As we noted above, it might be assumed that self help groups focus on individuals helping themselves. The term 'peer support' suggests groups connect individuals with their peers for mutual support. This distinction conceals the fact that both types of group are characterised by mutual aid and reciprocity, but it may cause the groups to be perceived differently. Does the peer support label have a less stigmatising and deficit-based nuance? 'Peers' are literally our equals, including people of the same age, with the same skin colour, job role and so on. Many of us rely on our peers for support in the workplace, college or club. Peer groups may be more diverse than self help groups, so for example their primary reason for meeting may be the arts, gardening, sports or community based activities. Those who have a social or economic rather than a biological understanding of mental distress might prefer to be with others who have a similar background or interest, rather than with people who share nothing more than a diagnosis.

Are self help groups more likely to be found within a Western individually-orientated culture, while peer support groups have more resonance with non-Western cultures and others who prioritise community? A report on the mental health service user movement in the UK referred to 'self help' (Wallcraft, 2003), while a more recent report on user involvement of people from Black and minority ethnic communities, spoke of 'peer support' (Kalathil, 2008). Does this suggest a cultural difference or is it merely the impact of ideological changes in mental health over five years?

Many self help groups set aside dedicated time for members to talk together about their problems, although, as mentioned above, they also get involved in other activities. Although peer support groups are more likely to focus on *doing* things together, as in the Bradford examples mentioned above, group members can talk during the natural breaks in their chosen activities and establish a strong ethos of mutual aid. If this pattern exists, it would suggest that peer groups might appeal to those less inclined to talk about their problems, for instance because of their gender or culture.

Service user groups:

The 'service user' label refers to another broad category of group. Wallcraft's study found that user groups carry out a range of activities, particularly self help and social support (79%), consultation with decision makers (72%), education and training (69%) and to a lesser extent, creative activities, campaigning, advocacy and other services
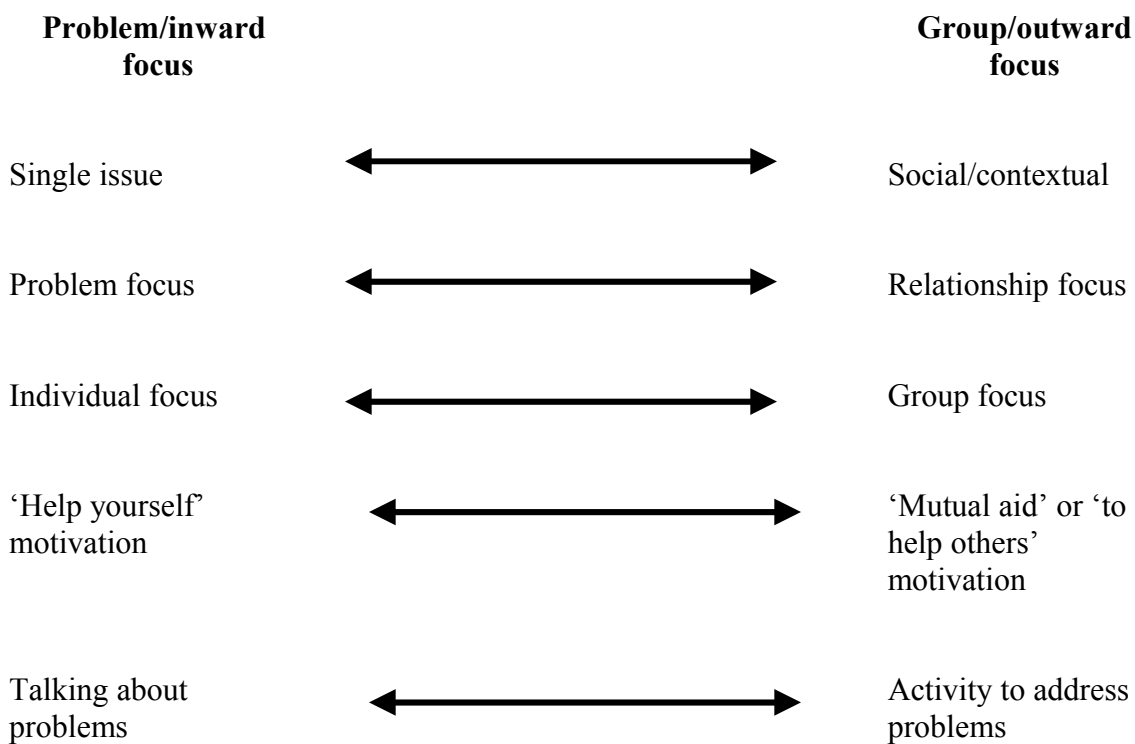
(Wallcraft, 2003). While mutual or peer support was perhaps the most important feature for members, the struggle for rights and better services was another high priority.
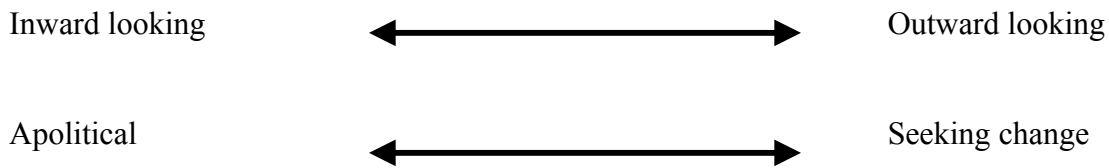
Relationships between the groups:

How do service user groups differ from self help or peer support groups? The 'service user' label suggests a group identity in relation to service providers and society as a whole, and with that may come connotations of togetherness. Some may identify a sense of shared oppression, milder than in the alternative label 'survivor group'. The emphasis on creating change in services, policies and attitudes may be greater.

Further research may uncover the truth in these suggested nuances, illustrated in the grid (Figure 1) below. Those groups described by members as self help may tend to begin their life towards the left, while peer support groups and service user groups tend to be on the right. Building a complimentary or challenging knowledge base about a diagnosis or condition is more likely to occur in a self help group because of the focus on sharing stories about diagnoses or situation. Many examples contradict this pattern, even in the discussion below about Black groups: self help groups have defied categorisation and may change over time as their membership, interests and circumstances change (Munn-Giddings, 2003). And we know that mutual aid and reciprocity characterise all these groups and are generally regarded as their greatest asset.

Figure 1: Spectrum of opposing characteristics in self help, peer support and service user groups

Problem/inward focus		Group/outward focus
Single issue	←――――――→	Social/contextual
Problem focus	←――――――→	Relationship focus
Individual focus	←――――――→	Group focus
'Help yourself' motivation	←――――――→	'Mutual aid' or 'to help others' motivation
Talking about problems	←――――――→	Activity to address problems

Inward looking	←————————————→	Outward looking
Apolitical	←————————————→	Seeking change

The changing context:

Self help groups, peer support groups and service user groups are examples of people coming together for a common purpose and so can be conceptualised as coming within the umbrella category of community action, along with neighbourhood groups and communities of identity or interest (Butcher *et al*, 2007). During the 1970's and 1980's, inspired by Freire and others, much community action involved challenging public authorities to achieve social or policy change. Traditionally self help groups have been located along with these groups within the third sector and voluntary action movement (Munn-Giddings, 2003). However, self help, peer support and service user groups are increasingly being located within the health and social care sector as the terminology of self help and peer support moves into policy initiatives. Health and social care practitioners not trained to understand the dynamics of self organising groups may be setting them up, but it is not clear if or how power and control in these professionally initiated groups can be transferred to their members (Chaudhary *et al*, 2010). Without member control, the nature of the group and its impact will be different, and while there is a place for professionally managed support groups, some commentators like Ockwell below, urge professionals to value what people with mental health problems do for themselves:

> '*Very often good ideas like peer support get picked up and officialised, and then lose a lot of the original value they had*.'
>
> (Ockwell, 2010)

At the same time, funding for service user groups is increasingly linked to 'involvement' activities in commissioning and service development, enabling funders to meet their statutory requirements. As a consequence, these groups can be frustrated by a lack of funding for their own priorities. This shift in location of self-organising, peer-led grassroots groups is a feature of the increasing control of government over our civil society; we wait to see what a new political regime will bring.

Self help, peer support and Black communities:

The historical, cultural and social experiences of Black people in the UK and in mental health services help to explain why their involvement in self help, peer support and service user groups differs at times from the mainstream population. 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. Historically, an ethos of individual industriousness and self-determination has been strong, as represented in the writings of Douglass and to a lesser extent DuBois who refused to accept a victim culture of hopelessness, despite the fiercely racist society of mid-nineteenth century America (McKeen, 2002). Many Black people felt then, as they did in Britain one hundred years later, that they had to become self reliant in the absence of help from others.

More recently, in the absence of culturally appropriate care within mental health services, Black communities have set up their own self help support services (Wilson, 2001). Self reliance and a wish for non-medical alternatives are by no means unique to Black communities, but the need to address racism and specific cultural beliefs sets them apart from mainstream self help groups.

At the same time there is a strong cultural connection between the Black 'self' and the community. Mutual aid is an integral component of many African cultures and Wilson notes that Black self help mental health groups are very much alive in the UK (2001). These are not the inward focused groups (on the left of the Figure 1 grid) where members come to help themselves, but are set up by people wanting to help others in their community. A founder member of Canerows and Plaits wanted to help people who were experiencing what she had experienced, and it never occurred to her that she herself would benefit, but she did (see Canerows and Plaits article). People helping others outside their group can establish a kind of serial reciprocity whereby a person receives help and 'repays' this at a later date to someone else (Katz and Bender, 1976).

Self help has been said to presume a context where people are free: social justice is a pre-requisite to self improvement. Society as a whole has a responsibility to ensure that individuals *can* exert personal responsibility. Within the mental health field, this argument has particular resonance. Many people from Black communities understand their mental distress to be associated with social and economic hardship (Callan and Littlewood, 1998). Therefore to address their mental ill-health, service users often feel it is necessary to address the wider context of social and economic disadvantage (Kalathil, 2008). This argument has good credentials: wellbeing is known to be closely related to structural inequalities within society (Friedli, 2009). Black groups who demand a broader approach by mental health commissioners are arguably leading the way to a more effective response to distress.

Service user groups and people from Black communities:

For many years there has been debate about the lack of involvement of Black people in mental health service user groups, even though their experience of mental distress is exceptionally harsh. Unmet needs, lack of trust and a lack of a welcome may explain this absence from mainstream groups, but it is also said that the experience of being Black cannot be disentangled from the service user experience. Black people need to come

together with others from their own background because mainstream user groups cannot comprehend racism and discrimination in the same way (Trivedi, 2008). Black user-led groups can help members build their self esteem, take pride in their heritage and improve their wellbeing (Seebohm *et al*, 2005). However, these groups have been scarce (Begum, 2006), hampered by a lack of financial or organisational support from outside their communities and perhaps by stigma within them. Only now is the Black service user voice beginning to get some recognition and support.

Acting together, people from Black user groups can engage with mainstream providers from a position of strength. Simba, a Black service user group in South London only participated in consultation exercises when they felt it would make a difference (Jones, 2008). The Canerows and Plaits group decided to shape their ward visiting scheme according to their own values of kindness, compassion and love, in preference to the evidence-based model of peer support adopted more widely. However, where community-specific groups are funded, this is increasingly linked to 'community engagement' activities for commissioners and providers, limiting their flexibility.

Not all Black people feel the same way about the need for separate groups. Even when Douglass wrote about self help in the mid-nineteenth century he recognised that cultures and ethnicities intertwine and connect in a dynamic way. Responding to the needs of service users, the Canerows and Plaits group has grown to be inclusive and multicultural, while keeping its focus on the needs of Black people. At the same time the political climate has changed. Statutory authorities are increasingly reluctant to fund community-specific groups, fearing they contribute to the fragmentation of our society, leaving those most at risk of distress least likely to get funding to help themselves.

Build on the benefits of self organising groups:

Self organising groups, particularly mutual aid groups, need to be understood in relation to their historical, social, cultural and political context (Munn-Giddings, 2003). Regardless of how they are described, many (but not necessarily all) of the self-organising groups that bring together people with a common interest (whether their distress is the focus or in the background) are likely to share the mutuality and reciprocity which builds positive social capital which, in turn, is associated with wellbeing and resilience (McKenzie, 2006). Groups not explicitly about mental health may also promote wellbeing and cohesion among those most at risk of distress, drawing in young Black men and others who would not otherwise engage.

Self organising groups enable members to do things in the way they find works best for them and their peers. Members gain control over decisions that matter to them in a way that may not be possible in much of their daily life. External support can be invaluable, but the role requires sensitivity to power and group dynamics (Seebohm and Gilchrist, 2008). Practitioners and funders can promote self determination and the benefits associated with it, but they can also quash or reject it. As unemployment rises, increasing numbers of Black people are coming into mental health services. We hope that those

funders concerned about the wellbeing of all our communities will seek out and support the self organising groups which can help to address their needs.

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