Effective Support for Self Help / Mutual Aid Groups (ESTEEM)

Stage 1 Interim Report
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Project management group

The research study is a partnership between Self Help Nottingham, Anglia Ruskin University and The University of Nottingham. The overall management of the project is led by:

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Project Advisory Group

A project advisory group, comprising the project management group and additional representation from the Department of Health, health and social care commissioning, practitioners, academics and self help / mutual aid groups, meets every four months to monitor the progress of the study and advise on issues arising.

List of Abbreviations

BAME	Black, Asian and minority ethnic
CDW	Community development worker
CE	Chief Executive
CVS	Council for Voluntary Services
ESTEEM	Effective Support for Self Help / Mutual Aid Groups
PCT	Primary Care Trust
SHN	Self Help Nottingham

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1. Introduction

Self help / mutual aid groups[1] are not a new phenomenon. Their roots can be traced back to the mutual and friendly society movements in the 19th century (Munn-Giddings, 2003) and in their current form they are usually seen to have emerged from the civil rights movements in the 1960s and 1970s (Williams, 2004). Unsurprisingly, they have undergone many changes in form and function over this time. Yet despite their long history they have been the subject of limited research, particularly in the UK, which has instead relied on evidence from the USA and Europe in its attempts to understand self help groups in this country (Munn-Giddings, 2003). Applying this evidence within a UK context is problematic, as it is widely agreed that self help groups develop in their own unique direction and manner in response to the political and economic context in which they exist (Karlssen et al, 2002).

The lack of knowledge about UK self help groups does not correspond to their scope or importance. The best available evidence suggests that in 2000 there were more than 23,000 self help groups operating in the UK and that this figure was rising, and would continue to do so, at a rate of 9% per annum (Elsdon et al, 2000). Furthermore the research that is available highlights the wide-ranging benefits associated with self help group membership. These include personal gains such as increased self-esteem, improved relationships, better ability to cope and decreased levels of isolation (Gray et al, 1997). There is also growing evidence that participation in self help groups can lead to improved health outcomes and more efficient use of health and social care services (Kryouz & Humphreys, 1997; Pistrang et al, 2008)

Despite these perceived benefits it is only recently that research in the UK has started to address issues relating to groups' development, maintenance, survival and support needs (Chaudhary et al, 2010). However, a good understanding of the ways that self help groups can evolve and the patterns of their life-cycles is important if professionals are to be able to work with and support them effectively. Yet the limited understanding of self help groups in the UK means professionals may not have the knowledge or insight they need to do this. Indeed Judy Wilson claims that professional services and self help groups occupy two completely different worlds and that this has often led the former to misunderstand the purpose and role of the latter (Wilson, 1994). However, since the publication of Wilson's 1994 study of self help groups and professionals, there is believed to have been an increase in the collaboration between self help groups and health and social care practitioners, and thus their 'two worlds' may have begun to be bridged (Stewart, 1990; Adamssen & Rasmussen, 2001).

[1] Although the term 'self help / mutual aid group' is felt to be the most appropriate, as it brings together self-responsibility with the reciprocity (mutuality) among group members that enables individuals to help themselves, for greater readability it is abbreviated throughout the remainder of the report to 'self help group'

1.1 Policy context

The current UK policy context may also provide a means of bridging the worlds inhabited by self help groups and practitioners. The socio-political context in which self help groups exist has been seen to have a strong bearing on the ways that they develop and relate to the state and public agencies (Munn-Giddings, 2003). In recent years a number of health and social care policies have begun to operate in areas traditionally occupied by self help groups. These policies, which include the Self Care agenda (DH, 2005), the Expert Patients Programme (DH, 2001), and the move towards increasing choice through personal budgets (DH, 2009), are all grounded in an ethos of patient and community empowerment and individuals taking greater control over their own treatments and by extension, their own lives (DH, 2006). These ideas of empowerment, choice and control have long been seen as the normative foundations of self help groups (Hatzidimitriadou, 2002) These policies also have a strong focus on the value of peers as a means through which understanding and knowledge can be conveyed. The Expert Patients Programme, for example, is implemented through a system of courses that are run voluntarily by people with long term health conditions, hence mirroring the experiential basis of knowledge sharing that takes place in self help groups. The courses specifically refer to participants' freedom to take part in the Expert Patients groups 'as much or little as [they] wish' (DH, 2001), again reflecting the voluntary ethos of input into self help group meetings. If the values on which public services rest continue to develop in this direction then opportunities for new alliances and ways of working with self help groups may begin to open up.

These health and social care policies are also part of a movement towards diversifying provision through the commissioning of services from non-traditional, community based providers, such as voluntary organisations or social enterprises that operate at a local level (DH, 2007). This approach to service delivery has the potential to affect the direction and development of self help groups some of whom may evolve into service providers.

The emphasis on community empowerment and service provision has been consolidated in the current Coalition government's Big Society agenda, which provides the cornerstone of their social philosophy. The Big Society aims ultimately to transfer power 'away from Whitehall, to local communities' and to provide opportunities for popular involvement in service delivery and any other matter affecting local, social life (Cabinet Office 2011). Again opportunities could arise for self help groups to extend or formalise their functions, although it remains to be seen how far funding and procurement processes facilitate such enterprise development in practice.

Successive governments have promoted the idea of public involvement in decision making through participation in consultation forums and planning processes (Department for Communities & Local Government, 2005). Unsurprisingly these procedures have made use of self help groups as a convenient means of obtaining lay and service user input into their discussions (Godin et al, 2007). Clearly this too could have an effect on

the activities, role and direction of self help groups as they become more involved in these practices.

These policy initiatives undoubtedly appear to open new opportunities for self help groups. However they also bring risks as these groups may become diverted from their core purpose and used instrumentally by policy makers or service providers to fulfill their own objectives.

1.2 Defining self help groups

Self help groups are believed to address virtually 'every conceivable condition' (Jacobs & Goodman, 1989) and display a 'staggering diversity' of forms and functions (Munn-Giddings, 2003). In light of this it not surprising that difficulties remain in defining them with any clarity. The task of appropriately defining these groups has important implications beyond mere academic enquiry, as decisions regarding funding and support or referrals from health and social care agencies may depend on whether an individual group falls within a particular definitional boundary. Examples of grey areas may exist between self help groups and: support groups which unlike self help groups tend to be professionally led; service user groups whose primary interest is service delivery (Borkman & Munn-Giddings, 2008); health advocacy groups which may have more overt political aims (Zoller, 2005); and more general community-based groups such as Neighbourhood Watch which may lack elements such as peer support that are generally regarded as essential to 'true' self help groups. However, there are no clear-cut lines marking these supposedly discrete classes of group.

The difficulty in defining self help groups exist in part because they frequently have numerous, concurrent aims and functions. Furthermore different members of the same group may point to different roles as being the group's primary purpose (Radin 2006). Paradoxically this very flexibility and subjectivity which makes them so hard to define, may itself be a defining characteristic of self help groups. In addition many groups exist in a state of on-going evolution, gradually morphing into, for example, a service user organisation or social movement (Borkman & Munn-Giddings, 2008) which may be regarded by some as qualitatively different (Trojan et al, 1990), but by others as frequently indistinguishable from a self help group (Wallcraft, 2003).

Despite the challenges it is possible to discern some characteristics that are generally agreed upon as essential, and the possession of most of which would point to a group's classification as self help (Wilson, 1994). These characteristics, which were largely applied in this study, are:

- The voluntary nature of membership of the group
- Self organising
- A shared experience or problem
- The provision of mutual support offered by and for the group members
- The control and ownership of the group resting with the members.

(Wilson, 1994; Elsdon et al, 2000; Steinke, 2000; Munn-Giddings, 2003)

Obviously these core features will themselves be subject to grey areas. For example questions might arise as to how similar the 'shared' problem has to be or whether it can be 'shared' by a third party such as a carer or relative. Similarly member ownership of groups will exist on a continuum ranging from absolute control to *de facto* control by a professional or agency, and hence a line will have to be drawn as to where self help ends and professional support begins.

Matters are further complicated because many authors have demanded additional criteria for inclusion within the definition which means that within the evidence-base about self help groups, like is not always being compared with like. For example Rootes and Aanes (1992) regard a democratic structure as an essential characteristic, and yet this is by no means a feature shared by all groups. And whilst the *ideal* group might be grounded in equality (Elsdon et al, 2000), in practice dominant individual leadership (Medvene, 1985) and authoritarian ideologies are often evidence of the contrary.

Similarly Levy (1976) states that true self help groups should have an 'express primary purpose' of providing support. Yet as groups frequently arise spontaneously and develop informally and organically along unplanned paths this would exclude those groups that have evolved into primarily supporting groups, but which nonetheless have never articulated this expressly. Indeed the informality that many authors see as a central feature of these groups, means establishing their primary purpose can be a difficult task. Many groups have a number of concurrent aims (Adamssen & Rasmussen, 2001; Gray et al, 1997) such as education, dissemination of information and campaigning, in addition to their supporting role. And as Gray et al's 1997 study exemplifies different group members may prioritise very different aspects of the group at different times. This subjectivity in how members perceive the role and value of the group may itself be a central feature of self help groups, to which, too rigid an approach to defining may be ill-suited.

1.3 Classifying self help groups

As discussed above (1.3) self help groups display a 'staggering diversity' in the UK. And so, efforts have been made to go beyond merely defining self help groups, by classifying them according to various different characteristics in an attempt to make sense of this diversity. Of course, as with definitions of self help groups, care has to be taken not to be too rigid in the application of typologies, as to do so would be likely to obscure rather than enhance understanding. The prevalence of 'cross-cutting' or 'hybrid' groups, that is those that appear to fit into more than one category, needs to be borne in mind, as does the fact that all classificatory systems are designed around ideal types, which may not exist in the rather messier circumstances of the real world. However despite these limitations, typologies can be useful as a tool for highlighting similarities and differences between groups.

At the most basic level self help groups are divided according to the issue they address, for example, mental health, physical health, carers, addiction etc. (Wann, 1995). This serves as a starting point for further classification. For example, Emerick (1991) divides

mental health groups according to their political ideology and relates this to their attitude towards mainstream bio-medical ideas about the causes and treatment of mental health problems. His groups range from 'radical', which see mental health problems as social and political issues, to 'conservative', which regard mental illness as a medical problem suffered at the level of the individual body.

Differentiating self help groups according to where they locate health problems is also the aim of Nylund's (1998) typology (cited in Munn-Giddings, 2003) which places groups along a continuum from inward to outward orientation. The former focus narrowly on their members and aim largely for personal, individual change whilst the latter takes a wider perspective and aim to make changes in the broader society.

Other typologies are concerned with different aspects of groups, such as their organisational structure. For example, Schubert & Borkman (1999) categorised groups according to features such as the extent of their independence and their epistemological grounding. The organisation of groups has also been correlated with the type of leader they employ, from charismatic, highly individual leadership which tends to give the group a vertical structure (Medvene, 1985), to diversified leadership, where responsibilities are shared amongst members, thus tending to give the group a more horizontal structure (Wituk et al, 2002).

Groups have also been arranged according to their stage of development, from 'fledgling' to 'mature' (Borkman, 1999). These developmental stages are believed to be related to various aspects of self help groups, such as the confidence members have in their own experiential knowledge (Borkman, 1999) as well as the extent of their formalisation and bureaucratisation (Medvene et al, 1999-2000).

1.4 Theoretical frameworks

The theoretical frameworks through which we understand self help groups are still somewhat under-developed, particularly in the UK. Analysis has tended to conceptualise groups from a 'treatment' type perspective (Karlsson et al, 2002; Hatzidimitriadou, 2002) according to which groups are understood as an alternative to professional health and social care services (Rappaport, 1994; Adamsen & Rasmussen, 2001). From this angle self help groups' main outcomes are therapeutic, benefitting individual members. This individual focus however only provides a partial picture of self help groups as it does not account for their broader effects at the societal or community level and the democratic, civic role that they are widely believed to play (Giddens, 1991; Damen et al, 2000).

A number of researchers have studied self help groups within more community focused theoretical models, raising questions that go beyond the groups' impact on individual members. Julian Rappaport (1994) has analysed self help groups within a narrative studies framework which conceives groups as normative, narrative communities and illuminates their role in identity formation and as sites for the creation of social values and norms. There is an inherent tension between this construction of self help groups and the dominant 'professional centric' model in which groups are viewed and their

effectiveness judged according to the narrower, more therapeutic criteria that underlie professional services.

Self help groups have also been studied from a 'voluntary action' perspective (Karlsson et al, 2002; Borkman, 1999). This approach has raised questions about the groups' role in network formation, their organisational structure and the social, cultural and historic context of their development (Karlsson et al, 2002). This more community focused approach is also in evidence in recent studies that have conceptualised self help groups as an aspect of health consumerism and health activism within broader social movement theories (Borkman & Munn-Giddings, 2008). These types of model provide the means through which to better understand groups' civic role and contribution to citizenship.

In conclusion, given the limited knowledge of the nature, characteristics and support needs of self help groups within a UK context the ESTEEM research study (*E*ffective *S*uppor*t* for S*e*lf H*e*lp / *M*utual aid groups) was designed to contribute to an understanding of self help groups and produce evidence-based guidelines for health and social care practitioners on how they can best support the development and continuation of these much valued groups in the UK.

2. Aims and Methods

2.1 The aims and objectives of the research study

This study started in May 2010 and is to be carried out in four stages over 36 months in two locations: Essex and Nottingham. The main aim is to produce evidence-based guidelines on how health and social care practitioners can best support local self help groups. To achieve this the study has the following objectives:

1. To develop a typology of self help groups
2. To explore and describe the form, focus, function, achievements and challenges of a sample of self help groups in Essex and Nottingham
3. To identify the training and support needs of self help groups during different stages of their development
4. To describe best practices in the support of self help groups and for the potential collaboration between self help groups and health and social care practitioners
5. To develop and disseminate good practice guidance on working with self help groups to relevant organisations and practices.

This Interim Report presents the findings from Stage 1 of the project. It provides a foundation on which the guidelines will be developed and refined in the following stages. Ethical approval for this stage of the study was granted by the Research Ethics Committees at Anglia Ruskin and Nottingham University.

2.2 Methods

The study is based on participatory action research (PAR) principles, with each stage informing the next and building on the stage before. Participants and stakeholders helped to review the findings from Stage 1 and to identify priorities for further exploration in Stage 2. PAR is defined as 'the study of a social situation carried out by those involved in the situation in order to improve both their practice and the quality of their understanding' (Winter & Munn-Giddings, 2001, p.8). This approach is valued for the way it helps to bring about research that has a practical impact. The study employs qualitative research methods to explore and understand the self help groups from both their members' and practitioners' perspective. In doing this we hope the guidelines will have as broad relevance as possible.

2.2.1 Identifying the self help group sample

As outlined in the previous chapter defining and classifying self help groups remains a contested area. However, it is generally agreed that there are a number of core characteristics intrinsic to self help groups:

- The voluntary nature of membership
- A shared experience or condition
- Mutual support

- Member owned and led

These core characteristics were used as a guide when identifying groups to participate in this research. In Nottingham, the existence of Self Help Nottingham (SHN), a charity that specifically supports self help groups, meant there was a current database of self help groups at this site. This provided a sampling frame from which the Nottingham groups were recruited.

In Essex, no comprehensive up-to-date database of such groups existed so a multifaceted approach was undertaken to identify groups here. This included searching local and national databases, checking websites of primary care trusts (PCTs), county councils and national organizations, and contacting practitioners working within community development and user involvement. This initial mapping identified approximately 42 groups, which were then examined in more detail to find out if they possessed the above core characteristics. Twenty-four groups were successfully identified for the sampling frame in Essex.

The next phase involved refining the criteria to meet the desired sample of 10 groups at each study site. A preliminary analysis of the data held by SHN and discussions with the Project Management and Advisory Groups on the appropriate focus for this study resulted in agreement that the sample should include:

- A range of health and social issues
- Established and new groups (not more than two years old)
- Affiliated and independent groups
- A number of groups specifically for people from Black, Asian and minority ethnic (BAME) communities.

In Essex a further search needed to be undertaken to meet these requirements. Ten groups from each site that matched the sampling criteria were then selected and invited to participate in the study. All groups agreed except one where the members felt that they would have very little to contribute as they did not want or need support from practitioners. However their group coordinator agreed to be interviewed and a further group was successfully invited to take part. Therefore in Essex limited data from an eleventh group was included in the study.

2.2.2 Interviews with self help groups

In order to address the second research objective (see 2.1) individual and group interviews with the study groups were undertaken between June 2010 and February 2011. In total 21 semi-structured interviews took place with the person (or persons) identified as the group leader or coordinator. This covered a wide range of roles from a formal chair or secretary to informal peer facilitator but for purposes of clarity the term ‘coordinator’ is used henceforward to cover all groups. Eleven interviews were conducted in Essex, instead of the ten as planned, as one group did not participate in the whole study, but it was agreed that capturing their reasons for not wanting practitioner involvement was

important. These interviews explored the nature, characteristics, achievements and challenges groups had faced, and lasted between 45 minutes and two hours.

In addition, 20 discussions took place with group members to further explore their purpose, activities and relationships with health and social care practitioners. These discussions were evenly split across the two sites and lasted between 45 and 90 minutes.

2.2.3 Interviews with expert practitioner

To address the third research objective, to identify the training and support needs of self help groups (see 2.1), 10 semi-structured interviews were undertaken with 'expert practitioners' working within this area. The Project Management and Advisory Group, along with suggestions made by the participating self help groups, identified expert practitioners to interview. These interviews explored the practitioners' motivation and experience of working with self help groups, and the training and support needs of such groups. Interviews were undertaken between February and April 2011 lasting between 45 minutes and two hours.

2.3 Data analysis

The interviews and group discussions with members of self help groups were thematically analysed at each study site, following the steps outlined by Mason (2002). The two researchers who had collected the data wrote up the findings from their own study site. A third researcher brought the analysis together. A draft report was shared with the Project Management Group for comment and further refined. Finally localised feedback seminars were held where the participating groups were invited to comment on the preliminary findings.

Similarly with the interviews with the expert practitioners the researchers at the different study sites thematically analyzed and wrote up the findings from the interviews they had conducted. A third researcher then bought the findings together in a draft report which was shared with the Project Management Group for comment, and further refined.

3. The Self Help Groups: Findings

This chapter presents the findings from the interviews with the group coordinators, and the discussions with the self help groups members.

3.1 Overview of the self help groups

The groups that participated in the study focused on a wide range of health and social issues. Broadly these came under the three categories of: physical health problems, some life threatening like cancer and others more physically disabling like myalgic encephalomyelitis (ME); mental health problems; and lastly, social issues such as isolation and discrimination including family carers and people from disadvantaged or stigmatized groups. Table 1 below lists the groups within these categories.

Table 1: Self help groups' health and social conditions

Physical health (n = 10)	**Mental health (n = 5)**	**Social issues (n = 6)**
Aphasia (1) Arthritis (1) Cancer (2): 1 generic / 1 specific Diabetes (2) Drugs & Alcohol (1) Epilepsy (1) ME (1) Vertigo (1)	Diagnosis specific (2) Gender specific (1) Gender and ethnicity specific (1) General (1)	Chinese men and women (1) Gay men (1) Parents group (autistic children and children with learning difficulties) (2) South Asian women (2)

However, most of the groups saw themselves as having a broader role beyond their primary focus. Nearly all health-related groups had a social role which could be particularly important for those groups whose members' conditions acted as a physical or psychological barrier to social participation. For instance the Aphasia group improved their members' speech but also reduced their sense of isolation and improved their well-being through playing games and doing quizzes. Meanwhile, the Chinese group felt that their weekly dances and social gatherings improved their physical and mental health.

Paid practitioners had taken a lead role in initiating nearly half the groups in both locations. For instance, two groups were set up by community development workers (CDWs) for people from ethnic minority communities after a local mental health needs assessment identified where support was most needed. The remaining groups were established by those directly experiencing the health or social issue, although often with some support from practitioners.

The size, venue and style of group meetings varied considerably. For instance, one group, that was struggling to survive, had as few as two or three core members who met regularly, whilst others had more than 30 members regularly attending. Venues ranged from community settings such as cafes and rooms in local agencies to hospital settings.

The style of meetings differed with some groups employing set, formal seating arrangements whilst others took a more casual and relaxed approach.

Many of the groups welcomed anyone affected by the specific health issue, including spouses, parents and children who were felt to be an integral part of the group. They attended with or without those with the condition and, in Essex in particular, sometimes played an important role in organizing or supporting the group, benefiting as much as other members:

> Even the carers that come through, they go away uplifted because we're not just talking about one's particular problem, we're talking about their problem as well.

> People who support people with long term illnesses, wives or husbands and whatever, they actually have a harder time than we do, and when they come you can see a little bit that the cloud has lifted.

Almost all the groups spoke of having fun during their meetings, sometimes laughing at the more absurd aspects of their situation:

> There'll be a lot of laughter. Yeah we have some very good laughs at times, even when it's supposed to be a depression group.

Nearly all the groups arranged some social activities, such as quizzes, along with activities outside the group like going out for a trip or meal:

> We had a Christmas lunch and meal for Dwali and Eid…it is not so much eating the food as sitting down together and very relaxing and talking and laughing.

The two parents' groups felt their fun-days, discos and parties were an important part of what they could offer to families and children whose learning difficulties often effectively excluded them from similar mainstream activities. However these activities sometimes also raised a few tensions as a number of groups spoke about the frustrations they had with some members who were not 'interested in the group or coming to the group', but who still tried to join the trips. They were often referred to as 'free-riders' and were especially resented.

3.2 Describing self help groups / group ethos (see also 4.2)

In Nottingham with the existence and influence of SHN there was an expectation that the groups would define themselves as 'self help'. However, this was not always the case as most groups did not use any single descriptor, but instead saw themselves in more fluid terms:

> Partly a self help group, partly a community group, it's a bit of both.

> We never really used the term 'self help group' in the beginning, we just wanted a group….our main aim is 'mutual support'…you could call us a community group, we're linked to the community.
>
> I don't know if it is a self help group, I mean I think it's a support group.

Similarly in Essex although nearly half the groups had 'self help' in their group titles, most of the members used other ways to describe their group, as the self help label often seemed inappropriate or insufficient to convey the groups' multi-faceted ethos. This is partly because members understood 'self help' as an individual activity. Instead other terms used were 'community' and 'support' group or 'peer support' and 'friendship' group.

Nonetheless many of the groups believed there was a strong shared group ethos, which emphasized their collective nature, unique understanding and expertise based on shared experience:

> We are all experts, every single one of us…and we contribute our knowledge, we give it to other people in the hope that some of our experiences may help other people.

This mutuality and their member-led ethos were frequently identified as the characteristics that differentiated such groups from mainstream services and contributed to a unique sense of attachment and ownership:

> We're not going to something that's been arranged for us…it's what we want, it's not somebody else's critieria that we're just going along to…so it's a different sort of basis.

3.3 Group processes and activities

The group processes and activities included; mutual support; information-sharing - both within and outside the group; and some activities specific to particular groups such as user involvement and aspects of service delivery.

3.3.1 Mutual support

All groups provided mutual support and most perceived this to be their unique defining activity. Many expressed feelings of isolation after, for instance, a difficult diagnosis, but in coming to a group of others 'in the same boat' they felt their sense of loneliness lifted:

> It was marvelous to come into a room and see all these blokes being in the same boat…[you feel] all on your own, you are the only person this ever happened to, you don't know what you're facing and suddenly you've got all this lot.

> I think it's the fear and isolation you know, before you [come to the group?]…I think I needed to talk to people that understood how I felt because unless you've got it you can't really understand what it's like.
>
> That tremendous boost you get when you first discover there's actually people just like you, it's amazing.

Once together, group members shared experiences with each other, often 'off-loading', confiding intimate details or their attempts to deal with practical problems. This sharing was pivotal to both giving and receiving support:

> We can give confidence to each other, encourage each other…it's like another family we got here.
>
> Emotionally you're drowning, you feel totally confused, you don't know what's happening to you, and by being able to disclose and share it, it takes you to a place where you think 'I actually feel lighter and now I am able to focus'. I am starting to understand that…it's ok to accept help.

The unique support derived from others enabled many members to find different ways of coping with their condition or situation, which in turn would often then be shared with newer members:

> I don't know if I'd have coped at all through some of the down times without the girls…I wouldn't miss my Tuesdays…that comes first.
>
> You see other people in a similar boat as yourself and then you see how they're managing. It's about exchanging. I normally use the analogy of a sweet shop, you've got lots of different flavours and we all have a different palate and from time to time when you have peers who've been through a similar journey as you and you hear about different flavours you think 'ah I've never tried that flavour, well that sounds quite nice, I'll give it a try'.

This reciprocal support was said to contribute to tangible improvements in many members' wellbeing and quality of life:

> Coming to the group gets you out, gets you on a bus, gets you down the shops, gets you to deal with people in everyday life…it is a step further to coming back into the big wide world and getting a job.
>
> It's helped immensely and turned my life around.
>
> [we've gained] self esteem and confidence, believing in yourself.

> At [the group] the information is really easy to understand for 'normal parents' and it makes you feel better not worse…. When you come to the group you realize that they can still have a life.

3.3.2 Sharing information

Information sharing was another crucial activity undertaken by the groups. It took place both within and outside of the group.

3.3.2.1 Sharing information within the group

In addition to mutual support, sharing information amongst group members was seen as another primary purpose for most groups, particularly for those with a shared health issue as this helped them to manage their health or situation better. Members shared practical and personal information about their condition and treatment, which provided a unique and valuable source of information:

> We'll say I'm on this or that, or talk about diet or health and then other people say 'oh I've had that' or 'oh I didn't know that'.

> A lot of people would say 'I've learned more about epilepsy in 3 hours than I have in the last 30 years'.

This practical and experiential knowledge then informed some groups' own health-focused literature, which again was highly regarded by its members. As most groups provided a space in which to share a broad range of information, members became knowledgeable about the resources available to them. Inspired by others, they often used their increased confidence and new knowledge to articulate their needs more effectively to practitioners, giving them greater access to services:

> One thing that the group does is give individuals more confidence when they approach their GP.

Access to information on entitlements in the Chinese group meant one member who was unaware of free eye tests before coming to the group and whose eyesight had been decreasing steadily was now enjoying renewed vision with new glasses, due to finding out about this entitlement. The assumption of cost had prevented her from accessing this service earlier.

The information shared within the groups was not just related to health conditions. A wide range of interests was covered in some groups, where speakers and learning ranged from wildlife to local history, healthy living to computer skills:

> We had a really interesting talk a little while ago about dementia…and this led on to a real debate about families and duties and government…It's a forum where you can feel confident and discuss things, a really wide range of issues.

Additionally, most groups valued the input of some professional knowledge, usually in the form of guest speakers invited to share their expertise in the groups' specific health issue (see below, 3.6.1)

3.3.2.2 Sharing information outside the group

Sharing information about the health condition or social issue to the wider community was another important activity carried out by most groups. Displays at local venues such as shopping centres and libraries were common along with events, often done in partnership with national charities and health and social care professionals. Some groups had even organized big local events with numerous agencies, community groups and voluntary organisations taking part. The focus of all these activities was to raise awareness of their condition or situation and reduce the stigma attached to it:

> What we learn from each other here, we can take out.

> One of our main aims is to educate other people about autism so professionals, people you know like scout leaders, swimming instructors, people like that that don't have any access to autism in their training…one of our aims is actually to help educate those types of people and make them understand a little bit about the children…autism awareness.

> We got involved with a diabetes day and when it's diabetes week we always go into the local library with the nurse and we get people to have blood tests to test whether they may have diabetes or not.

> We've organized a quiz night at the local community centre…it is a way of informing and raising awareness.

> It's amazing…the number of people who knew very little about how they should look after themselves, and we were standing there helping them, giving them leaflets and they didn't know, they didn't have the information from their surgeries or anywhere.

Sharing information with the wider public was an important way of attracting new members. Many groups had helplines or contact telephone numbers and nearly half produced a newsletter, which contained a range of information about national and local issues. A number of groups also had their own websites or were advertised on those of other organizations. In contrast, two of the BAME groups preferred to advertise through word of mouth, as this was regarded as the most trusted form of communication:

> We rely on word of mouth a lot, rather than [leaflets]…people need to find the benefit and then they can tell people.

3.3.3 Community networks and user-involvement

Community network activities was an area particularly well-developed in Nottingham, as many groups were working with a wide range of agencies and organizations, including schools, colleges, pharmacies, voluntary organisations, councils, welfare services and the private sector. Members participated in a wide variety of local organisations such as book clubs, theatre groups and tenants' associations, and acted as school governors, volunteers and on church committees. Information from these associations was often then shared at group meetings:

> Sometimes we get information from other groups or from community centres about some trips. We will come here and tell the group about it and see does anybody want to go.

Consequently many of the groups in Nottingham felt that they were making an important contribution to the local community:

> We started going out…and attending community meetings…we started working in association with other groups in the community…we've gained community status…we are a link between our local community, employers, professional groups.

User-involvement was another activity a number of groups, across the two sites, were involved in. For instance, one group, supported by specialist nurses, had many opportunities to feed back their views to user-involvement staff, the PCT, researchers and others. This group was interested, well-connected and easily accessed by those who wanted their views, so much so that the coordinator thought that they had perhaps given more help to the PCT than they received. The coordinator and wider group members attended a variety of forums, locally and even nationally, determined to make an impact on clinical services despite the challenge:

> That is the hardest thing in the world, actually feeding it back to these people. They're never around, they hardly ever meet, and that actually is my advantage that I do sit on this National Health Board, because that does have some clout.

However, many group members did not have the health, resources or time for engaging in consultation processes, particularly those from minority ethnic communities:

> You exclude anyone who doesn't have a computer, secondly those who don't read English. It says, you can phone in and ask for a translator, you know, if you don't speak English, you don't read, how do you know to pick up the phone to ask for it? You can't.

In addition there was the potential for user-involvement to be perceived as tokenistic, particularly when individual participants did not feel they genuinely represented a

broader, more collective perspective or when service providers only invited compliant views:

> I'd like to see us have voices that can be gathered together in an effective way...I didn't want to go along as just one person having a view, I wouldn't be on the strategic group unless I was in a network of some kind where I could consult with other people.

> We were very unpopular with the PCT because we tend to enquire about things …they feel you're harassing them.

3.3.4 Service delivery

The small, informal nature of many self help groups, as well as their focus on mutuality and reciprocity suggests that they are not involved in the kind of service provision typical of mainstream agencies. Two groups appeared to be moving towards this type of role as they had evolved from small groups offering informal mutual support to very large groups hosting drop-ins and other family services often in partnership with other local agencies. Both groups, however, still emphasised the essential role of peer support and experiential knowledge within the activities they offered:

> One big family there to support each other…and we come together and we give advice to each other.

3.4 Group structure and organisation

3.4.1 Groups' structure (see also 4.3.3)

The groups displayed a broad range of structures, from registered charity to no formal structure. Table 2 outlines this range, illustrating that it was more common for groups to have at least some structure in place, usually consisting of a constitution and management committee.

Table 2: Self help group structures

No formal structure (n=7)	**Some structures in place (n=12)**	**Registered charity (n=2)**
3 physical health 3 mental health 1 social	6 physical health 3 mental health 3 social issue	1 physical health 1 mental health

Those groups with no formal structures on the whole prioritized their informality and independence and felt formal structures were incompatible with their member-led egalitarian ethos:

> There's no structure to the group…we have no funds behind us, it's just a group that meets.

> We don't have officers, we don't want it to become a big hierarchical agenda driven group – we don't want to get to be talking to one another formally
>
> It might create a psychological difference that if somebody has the position of chair…it could feel possibly uneasy.

Some groups were willing to forego the benefits of funding in the interests of maintaining their lack of structure:

> If you ask for funding you're tied to things that you've got to do and we thought, we don't want to do that.

Conversely, those groups with some structures in place, although cautious of the impact of formal structures, recognised the benefits:

> To enable us to get funds we had to form a committee and get a constitution…before it was all quite informal and then once you've got a constitution it can make people take things a bit more seriously…it's like putting a barrier up in between people…you have to have all the right buzz-words and you get to know how things work.

The two groups with charitable status felt such an organisational structure was beneficial for funding purposes and credibility:

> We got the charity status… I never thought we'd get it, being such a small group, when that came I was ahhh…it made it feel as though what we started, the purpose behind it, it meant more because we'd been recognised, you know, from an outside body, which was even better.

However, in a later interview the coordinator from the above group described how the administrative responsibilities had become burdensome and questioned whether charitable status at this early stage in their development had been the right approach:

> I think one year was too quick…It is a registered organisation, you know, you can't just run it willy nilly, you've got to record everything…whereas before we were registered…nothing was ever recorded.

Despite the concerns raised about formal structures most groups who had adopted some structure still maintained their egalitarian ethos, and frequently would refer to their groups as a 'community' and 'family', where they felt 'relaxed' and 'at home'.

3.4.2 Decision-making

On the whole groups made decisions in an informal way, usually by 'throwing things out to the group' at meetings. There was however some variation in the extent to which decision-making could be said to be democratic, in terms of taking all members' views

equally into account. For instance, sometimes coordinators might make a decision by default, in the absence of views from members, whilst it was more feasible for members to be involved in the decision-making process when there was a core group of members regularly attending meetings and/or on the committee:

> That is the advantage of having a small core group…We take on more responsibilities, when somebody new comes we ensure we take care of them, somebody who has been around will keep an eye on them.

> Instead of one person trying to do it all, you know, we try to delegate and let other members of the group...have part of it as well, or take part in it as well, so it gives them a little bit of a sense of responsibility, and they go away all positive.

3.4.2 Leadership and collective involvement

All groups, regardless of their size and structure, had organisational tasks that needed to be undertaken. For instance, meetings had to be organised with venues, refreshments and reminders to members; newsletters had to be written and circulated; administration and accounts had to be kept up to date; fund-raising and awareness raising activities required liaison with a variety of agencies and preparation. In addition to organisational responsibilities there were more emotionally demanding tasks, as many groups had helplines or informally provided one-to-one support. Consequently even those groups with no formal structure had one person who took the lead in organising the group and its activities and was identified informally, as the group coordinator. Undoubtedly this role required a huge amount of passion and commitment, often motivated by the desire to make a difference:

> It's a huge amount of time, but you've got to have the passion to do it. If you're going to be involved in something you've got to be passionate about it, and I was passionate about the group from the beginning.

> I thought, I suffered myself and I didn't really get much out of the [mainstream] service. Now I want to help other service users, so it was a sense of vocation.

Some group coordinators, particularly in Essex, found achieving collective responsibility for group tasks challenging. On the whole those groups that were set up by a few people working together often had a strong emphasis on collective ownership and decision-making by consensus. Whereas in those groups that had been set up predominately by one individual, member involvement was usually found to be less evenly balanced. Several coordinators admitted to finding their roles burdensome at times:

> I sometimes [feel] shall I bother or not bother? Sometimes I don't want to do the job.

> There are times when I feel exhausted or feel down, I would desperately like somebody to come along…just to hold the key in case I'm ill or need a break.

> It's led to me having ill health over the last six months…without the support it can get very demoralising sometimes.

Across the groups poor health of members could also have a great impact upon collective involvement. Also some group coordinators were concerned about the group's reputation and image and therefore found it hard to relinquish control, particularly when groups were moving into the arena of service provision:

> I obviously take the ultimate decision and I like to see things myself, I like to check things out…I insist on things being done to a standard.

> We've built up a very, very good reputation, I cannot sacrifice that.

3.5 Funding

The biggest expense for groups was the hiring of premises. Other expenditure included transport costs, such as to attend meetings or days out and payment of guest speakers' travel expenses. On the whole most groups received funds through their membership fees or fund-raising activities and some, mainly in Nottingham, received 'benefits in kind' with reduced rent for premises and help with publicity. Nonetheless, a number of groups were struggling financially and were concerned about their survival:

> Funding can sometimes be a problem for groups of this size because we're not big enough or established enough to attract big funders or the charitable donations of big companies…it would be absolutely awful if the group had to fold over funding.

> We wouldn't exist if we didn't have funding.

In some cases groups had chosen not to apply for funding in order to maintain independence and avoid being accountable for their activities to an external organisation:

> We can run on almost nothing…We didn't want to go down that route with funding because once you start you've got to keep applying and we didn't want to do that.

> Funders expect a certain structure [which] could take the group in a direction it didn't want to go.

However, a very small number of groups, particularly in Nottingham, who were receiving external grants did not feel their independence had been compromised by receipt of these funds:

> No they've just left us [alone], we've got the funding and it's up to us, they're happy with that …they don't keep tabs on us.

Three groups who had received substantial sums had either turned down the option of applying for larger amounts, or in one case expressed reservations about spending the grant. This latter group had existed in the past on very little and believed that self help groups had 'simple needs' and should not just be 'all about days out'. The other two groups had been concerned about the added responsibility entailed in receiving larger amounts, particularly the additional requirements for accurate account keeping:

> I'm ok with putting funding bids in but it's not just the money…it's all the legislation, all the admin stuff, the behind the scenes work.

Overall most groups expressed the need for support with funding applications, as the process was generally seen as a 'big headache' and groups were keen to attract funding that would enhance their group without imposing incompatible requirements.

> Every year we start to bang our heads and say 'where will the next funding come from?'…and every one is different, each one has to be worded differently.

> [We want] assistance with funding applications which don't attempt to destroy our ethos and the way we like to run.

3.6 External relationships

The groups had various kinds of relationships with external organisations and individuals, which are discussed below.

3.6.1 Relationships statutory services and health practitioners

There were a number of examples where health practitioners enabled or enhanced group activities with guidance, practical support, useful networks and fund-raising opportunities. Often these relationships were mutually beneficial, as group members helped practitioners by speaking at health awareness or consultation events. Good relationships usually formed over a number of years, as the practitioner may have been responsible for initiating the group or they were fully supportive of the member-led ethos. Specialist nurses came in for particular praise:

> She [specialist nurse] always says 'you're the experts'.

> It was lovely…she [specialist nurse] could give her advice and she knew everybody.

> Without [specialist nurse] we'd be in a mess…she knows her way around the NHS that's for sure. She's got a lot of ideas [about running groups] and little things we might like to be doing.

A number of groups would invite consultants and other health practitioners to speak at their meetings. One group had taken this further and appointed a respected doctor in their condition to be their 'special advisor':

> He helps a great deal…he came to our AGM this year for the first time…and he gave a talk and that was brilliant. When members have any health issues, then I'll say, 'Do you mind if I pass this on to Dr. [specialist advisor]'.

However, there were some examples of less positive experiences with health practitioners and statutory services. For example, two groups began as part of mainstream mental health services and both had been through a challenging transition into a member-led group and had experienced difficulties with mental health services engaging with them:

> I believe its very difficult to get a relationship with the [Mental Health] Trust, they're just not available.

A common frustration felt more strongly amongst Essex groups was the lack of respect and recognition some groups received from statutory services, particularly health practitioners:

> I feel most of the professionals are caring, they do want to help their patients, but I can't understand why they don't have the confidence in peer support groups.

> The hospital, they know we exist…We are a group, nobody cares about us, that is what I think.

This frustration was exacerbated further when groups felt they were filling a gap by providing information and support, but still not receiving recognition:

> …[the group] will save money for the Trust, it will keep people out of hospital…Just because we're service users doesn't mean to say we're not providing a service for the same people as they are.

3.6.2 Relationship with GPs and other clinicians

In Essex, many groups struggled to find practitioners willing to promote their groups. They felt that GPs and clinicians were particularly resistant:

> I took a poster into my doctors, it was up one day and it was down the next.

> I've left posters up at the [clinical] centre and I've never seen them on the wall.

One group coordinator felt the professional term 'referral' could deter professionals from informing their patients about the group, as it carried with it a sense a responsibility:

> I know professionals use the word 'referral' and when they use the word 'referral' they feel responsible. But…you can only make informed choices if you've got the information and what we're saying is we're not telling you to send your patients, we're telling you to inform your patients that they have a choice that this exists.

Some groups in Essex had wanted to engage GPs and clinicians to share their experiences by inviting them to meetings, but in most cases this had been met with limited response. Many members from the minority ethnic groups had poor experience of the GP interpreting service with it not being properly advertised and interpreters' not receiving payment. However there were a number of examples in Essex where there had been positive relationships with GPs and clinicians. For instance, members who talked of the group to their own GPs often received a better response, and one group found having the PCT logo on their posters helped:

> My GP is brilliant, she'll tell people.

> We had trouble getting the poster up [then] people said 'oh are you people from the PCT?', [who] let us use their logo…That helps a bit.

In addition one minority ethnic group received direct referrals from psychiatrists who felt the group was offering culturally appropriate support and understanding:

> We do get very, very good reports from them, from the psychiatrists because…when you can't put a finger on the clinical situation a person's mental health may be subject to cultural issues that they have and the social surrounding.

It was recognized by most groups that consultants are under enormous pressure of time, focused on how they can deal with clinical problems, which left little time to talk about their experiences with self help groups:

> There's only so much you can communicate when you're in with your psychiatrist, so the more wider experience they get the better they understand how to treat us, how to approach us, how to give better care.

Experiences of GPs and other clinical practitioners in Nottingham were generally more positive than in Essex, possibly because they had the support of SHN to promote the value of self help groups. Nonetheless some groups felt aggrieved that certain professionals still appeared to be 'obstructive' or 'lukewarm' in their attitude towards self help groups. This was a particular problem for mental health groups, whose aim had been to complement mainstream services by acting as a 'stepping stone' for discharged patients. However they had had little response from health workers by whom they felt they were being 'sidelined.'

3.6.3 Relationship with community development workers (CDWs)

Two groups were set up by CDWs employed by the PCT as part of their remit to promote race equality in mental health under the Department of Health '*Delivering Race Equality'* programme (DH, 2003) and both held the position of coordinator within the group. One CDW explained her 'subscribing' approach whereby she aimed to ensure member ownership from the start, rather than set up a group and try to transfer ownership later which, she argues, never works:

> It's self help in responding to their needs, because we always adopt the *subscribing* approach rather than *prescribing*. You know prescribing is like, we set it up for you and you come, this is the service we offer you, and then you need to learn how to take ownership of it…we felt that it never works because it doesn't reflect what they are searching for, their needs….whereas with this, OK, we are here to support you but you subscribe to that and you then draw up how you want to run it, what is more important, and from that they actually would learn how to manage it themselves, so that I think is more sustainable.

This CDW spoke of 'self help with a little bit of help' because the group needed help to establish themselves 'but not a lot of help' as members were helped to run the group themselves, with outside support limited to funding applications, monitoring reports and other complex functions. Both CDWs described themselves as trusted members of their community, respected for their skills and connections with statutory services and one described herself as to some extent distanced, enabling others to perceive her as one who would respect confidentiality within their tight social network:

> They have this complete trust in me, and also maybe because I always deliver... [I] keep a distance from or do not socialise with them….as much as I live here in the town, I will meet them for a cup of coffee and things but I do not go beyond that, so that there is that bit of professional input there, they feel that they are confident enough to confide in me and this stops there and things get done.

Both CDWs were deeply committed to the work because of the need for and beneficial impact of the groups, which explained their continued support despite their redundancy and in one case, a new job. They felt that the PCT failed to take on board the need for long term community development to sustain self help/mutual aid for greater wellbeing in ethnic minority communities:

> That is quite sad because it was funded by the Department of Health under the Delivering Race Equality and that scheme ran out last year….the PCTs are supposed to then absorb and continue the work, because any community development work is not short term, you can't put in two years work and expect that to be sustainable…I think it is timely to then look at community development in a very different way, look at the sustainability of it.

3.6.4 Relationships with affiliated organisations

Eight of the 21 groups were affiliated with national charities. Positive experiences of affiliation included inspiration, encouragement, guidance, the opportunity to network, facilitating new membership, access to information resources, practical help (e.g. covering public liability insurance, referring a volunteer to help the coordinator) and the added status and credibility that came with the name. Coordinators were more likely to feel the benefits of the guidance and assistance, as they were generally more outward-looking than their members, and had more interest in the national and regional activities:

> We are independent but we also come under their umbrella, so when it helps us, when we do some fundraising and we use that name it can work to our advantage…[The relationship is] brilliant, because they include us in everything. …It's in my control, it's up to us.

Negative experiences included excessive control, lack of interest in the support role of local groups, lack of communication, disrespect and a sense from some members that the charities took too much of their hard-earned funds:

> It's bankrupt, it's hardly helped us, hardly helped me at all. All I have is their name…People commented on how unenthusiastic he [representative from the national organisations] was, how he didn't stimulate, he didn't inspire, he gave the impression that the national office was struggling and he came to kind of sign everybody up to [the national organisation].
>
> It's almost as if we're not allowed to say or do as we please. It's almost as if they see us as an arm of their organisation and almost as if we're only there to raise funds for them.
>
> The last time I had contact with them and I said we're affiliated to you, he said, 'What does affiliated mean?'
>
> I'd like a more caring attitude I suppose, is what it boils down to, I'd like one that was more concerned about the jobs we were doing as a support [group] and in education…rather than just a money box for them.

3.6.5 Community resources available to groups

3.6.5.1 Self Help Nottingham (SHN)

SHN was by far the most frequently used source of support mentioned by those groups in the Nottingham area. For most this was the first place they would contact with any query or problem when they felt they lacked the necessary capacity or skills. The support offered was practical and tailored to the needs of the group in a sympathetic way. Group members mentioned having accessed various training courses, for example regarding finances and funding. The 'networking events' SHN hosted were particularly valued as a

way of meeting other groups whom they could contact and learn from. Two groups from Nottingham had been through periods of crisis from which they felt they would have been at risk of folding in the absence of support from SHN:

> We went to SHN not long after I joined. We had reached an all time low at that point when we were on the point of collapse…and through SHN that's how we managed to get a lot more community status because SHN managed to get us on our feet again and also managed to get us invitations to lots of groups and meetings and things like that, and then we managed to become a lot more successful, they did manage to help us overcome that time.
>
> You know they were the only ones who were interested in us…if it wasn't for SHN we wouldn't be here now.

3.6.5.2 Council for Voluntary Services (CVS)

The local CVS agencies played a limited role in setting up or supporting the study participating self help groups. Very few groups knew or understood what CVS could offer, although two groups had used CVS and spoke highly of them in relation to good value meeting rooms and support with account-keeping:

> They invited us to do these courses…somebody sitting there telling you where to put your account, how to reconcile the banking, it's very, very new and it drives us crazy, so it's this kind of help is there and even…if I go last minute I have this problem they would [help] me, [Name] is brilliant in CVS.

4. The Expert practitioners: Findings

This chapter presents the findings from the expert practitioner interviews. It begins by briefly outlining the professional role of the practitioners who participated. This is followed with how they describe self help groups and how they perceive the role and skills of practitioners working with these groups. The chapter ends with some of the challenges that face practitioners when working with self help groups.

4.1 Overview of the expert participants

In total ten practitioners with expertise in working with and supporting self help groups were interviewed. These participants worked in a variety of different settings across the UK with varying levels of involvement and direct experience with self help group. They comprised:

- Chief executive (CE) of a national charity with affiliated self help groups
- Regional manager for a national charity with affiliated self help groups
- Area manager for a national charity with affiliated self help groups
- Grants manager from a local funding body
- Previous director of a charity that specifically supports self help groups and who has published widely in this field
- Training and development manager from a charity that specifically supports self help groups
- Service manager from a national mental health service provider organisation that has a strong ethos of user involvement
- Coordinator of a national network of Black, Asian and minority ethnic (BAME) mental health service user groups
- Community development worker (CDW)
- Community development worker (CDW).

4.2 Describing self help groups (see also 3.2)

Practitioners pointed to a range of defining features given to describe self help groups, including the shared experience of members, the group ownership of knowledge and the beneficial impact on members, as the following extracts illustrate:

> People…who share a particular problem or social issue, coming together for support and change.

> This is our explanation of the world, this is how we see it, and this is what we think our problem is, hence the solutions are different from the ones that [medical expert] has talked to us about.

> The idea of self help is to re-skill, re-establish confidence and self-esteem and give people that step up to going back to what they really should be able to do on their own.

Two participants working within mental health spoke of 'peer support' rather than 'self help' groups and the grants manager felt self help groups fitted within the overall category of 'community groups':

> We just see all the groups as community groups that are out there doing good work in the community.

A number of participants felt the language around self help groups can be misleading due to the different ideologies underpinning it. For instance some participants felt 'self help' may be interpreted as an individual activity, whereas others felt it was an academic and 'contested' term rarely used at grassroots levels.

One CDW felt there was an important distinction to be made between what he called 'pure self help': the smaller, informal group, for instance of people with phobias, where mutual support is the primary function and minimal funding is required, and 'community self help': the potentially larger group, for instance of refugees and asylum seekers, which seeks funding to deliver support to peers in great need:

> I'm saying there's one which is tender ready, ['community self help'] and there's the other one ['pure self help'] which is, 'oh wow we are on our own aren't we?'….we will do it our way if we're not getting any resource.

While some practitioners felt the choice – and discussion - of terminology irrelevant, others argued that clarity was important so that potential members and those working with these groups can understand and relate to each other:

> Terminology is important, that both the members and the professionals who might relate to them can understand it, and it is not that simple.

Although there was variation in the ways participants described self help groups, a number of core features were identified which included a member-led ethos, shared experience and mutual support:

> A facility where people who are experiencing similar difficulties can just get together on a regular basis and support each other by sharing experiences.

Groups were recognised as an invaluable source of information for members regarding their health and treatment. It was thought that information from members could be passed outwards to providers and commissioners, helping to improve services. One participant summed up this process, which she felt rewarded her for her work with self help groups:

> When I see people benefit from the support they get from other people, but also benefit from *giving* other people support and seeing how that can boost their self belief and then ultimately turn what was a very negative period of their life into something positive and be able to see that, and the strength that gives somebody to then move on to address all sorts of area in their life, because it just gives

> people that boost. It can completely turn things on their head, so that something that actually was negative, holding them back, ruined their self esteem, can literally do the polar opposite in all of those things.

4.3 Role of practitioners vis-à-vis the self help groups

Participants identified a range of activities and skills needed to support self help groups. This included practical support and guidance; interpersonal skills; fund-raising support, evaluation and accountability. Finally, participants had some thoughts on the challenges working with and facing self help groups.

4.3.1 Practical support and guidance to self help groups

A range of practitioners including health visitors, midwives, specialist nurses, social workers, occasionally medical consultants, CDWs and voluntary organisations like SHN were identified as being in a position to offer self help groups practical support. This might include free or low-cost venues, publicity and help in attracting new members, often small interventions but invaluable to the groups:

> They didn't need a lot of support or backup, but just a bit made *all* the difference.

The model of support provided by SHN was generally believed, by those who knew it, to be an effective way of meeting the needs of self help groups. All new groups in the Nottingham area receive a starter park that includes information about forthcoming training and events and either a £50 grant or help with publicity, along with the use of SHN's premises as a meeting venue. SHN offers on-going practical support, guidance and training, opportunities to network with other groups and community organisations. At a later stage of group development, members are given a means of promoting their public profile through a widely distributed self help directory:

> It's not just an up-to-date publication [that's] free…but it gets out there…so often these publications are done and they're not accessible…so [it's]…making the groups visible and some clarity about what they do.

Most of the remaining participants' organisations had mechanisms in place to provide support for groups affiliated with them. For example, the CE of a national charity sought to offer practical support and guidance in the form of network meetings, training, a bi-monthly newsletter, a helpline, resources for fund-raising, use of their charity number for fund-raising and access to paid staff for further advice. Likewise the mental health service manager offered leadership training and linked groups with training from the Workers Education Association, which included IT, assertiveness and one-to-one goal setting sessions. Even the grants manager of the funding agency, whose relationship with groups was more task oriented and discrete maintained on-going supportive contact with a number of groups.

4.3.2 Interpersonal skills needed to support self help groups

For those participants closely involved with self help groups a range of key skills were identified as important when working with them. For instance, one CDW described being 'immersed' for two days a week with a self help group, which involved maintaining a close 'professional' relationship with the group, balancing the need to be responsive but also challenging. One participant felt she had benefited from being skilled in facilitation and knowledgeable about the experiences that group members shared:

> I have to learn quite a bit about the groups, as well as individual's conditions and experiences, about management styles and that sort of thing.

However, the training and development manager from a charity that specifically supports self help groups felt her role required building capacity within groups, so being informed and knowledgeable about the groups' conditions was not deemed necessary:

> If you understand the fact that you don't share that issue that they come to you, you don't even need to know very much about it, what you want to do is foster a relationship between that person and other people in the group and not with you.

Participants spoke of encouraging members by increasing their self-confidence and enabling them to take the lead. To do this one participant would essentially 'put people on the spot' so they take up new responsibilities, whilst creating 'a sense of security,' by keeping an eye on how confident and safe members were feeling in their new roles.

The service manager described her role as 'Mrs Sunshine' counteracting negative comments by putting issues into a wider context and questioning judgmental attitudes. The two CDWs described their 'old fashioned' approach to community development, which aims to open up opportunities for critical reflection thereby increasing political awareness among 'people on the street'. They found that by working closely with and alongside self help group members they could have a more educative and creative role:

> It's being enmeshed in their role, the work that they do rather than from the sidelines…you consequently make it far more educative…you're learning, you're working together.

Some participants felt their role was often more of a 'broker' and 'mediator' to help groups negotiate with the agencies around them. Much of this is about tackling power differentials between statutory authorities, service providers and groups, but it is also about bringing together people with different perspectives and experiences to increase mutual understanding. For example, the service manager brought the self help group and the manager of its new host agency together once a month to discuss current issues. Her role at these meetings was to act as interpreter, enabling both sides to understand what was being said. These roles were described as 'really intense' and 'immensely difficult'.

4.3.3 Developing self help structures (see also 3.4.1)

Some but not all participants suggested groups should have a structure. For example, the CE of a national charity said that her organisation required all affiliated groups to adopt the same constitution, which was continually being simplified to meet their needs. As the groups' funds were included in the accounts of the national charity, it was imperative that they had systematic and transparent financial management. However, the aim was to offer sufficient flexibility to enable the groups to operate as they wished:

> Not to lay down so many rules and regulations and red tape that a group can't make decisions for themselves and can't do what they as a group feel is appropriate for them.

Those groups who did not choose to adopt the constitution could opt for the looser relationship of 'association' instead of affiliation. Support was given to affiliating groups to establish their constitution by phone and wherever possible, by a visiting worker.

Another national charity had a similarly flexible approach if groups wanted to use its charity logo and number, only requiring that the associated groups had a bank account and some sort of 'committee':

> They need to have formed some sort of committee in the sense that there are regular meetings.

A more rigorous approach was required by another national charity as groups were required to have a chair, treasurer and secretary, who must go through an official training programme. A 'standard' set of activities was also required, including monthly meetings, awareness and information days and fundraising. The training and development manager, who had extensive experience of working with nationally affiliated groups, had seen this type of controlling approach lead to serious problems and even 'explosions' in the relationship between parent organisations and their local groups.

The mental health service manager had encouraged the group she supported to adopt charitable status at an early stage. Although the group was subsequently experiencing significant difficulties and the Chair felt overwhelmed, blaming the bureaucracy required by charitable status, the service manager felt this had been the right decision. She spoke about the group as a service, and felt that they fit well with Big Society policies:

> They're just what the Big Society's all about.

The grants manager highlighted that affiliated groups often were 'more organised' with 'more solid documents in place'. However, the CDWs were uncomfortable with this pressure to create structures in order to attract funding or contracts as they felt this threatened the fundamental nature of self help groups:

> One of the real downsides for me is the professionalization of groups having to meet X and Y requirements to meet funding…[to get] tender-ready…a ridiculous set of requirements.

4.3.4 Fund-raising to support self help groups (see also 3.5)

The area of support which most challenged participants directly working with self help groups was around fund-raising. Even small groups which do little other than meet regularly were said to need some funding to cover their expenses, while ambitious groups, for instance of refugees and asylum seekers, wanted more funds to help their peers experiencing dire hardship. Participants spoke about developing the capacity of group members by working alongside them, 'hand-holding' so they can see how facilitation, administration or funding applications are done before they try it out themselves. Despite these efforts group members were often said to remain overwhelmed by the process:

> I provide them with all the bits and pieces, hand it to them and then it goes nowhere.

One participant whose organisation provides training in funding applications outlined that when people 'took the leap' and completed the course they were generally very successful in their applications. However, many groups would not attend the training, either through fear or complacency, and preferred to be dependent on support workers to go through the process with them:

> If it's an online form we sit there, we work out what they want to say…and I'll say, 'when you do the next one you'll be better placed', and then I get a call when the money's run out saying, 'help we've got not money left, can you help us make an application?' and then it happens again and I know my job is to skill up people and I feel guilty that I, you know, haven't managed it with the group.

A number of participants recognised that funding applications required nuances of language that will appeal to the funder and which cannot be taught easily to group members. Inevitably this creates a dependency, which may then be exacerbated if a group acquires funding before it has sufficient administrative skills and systems to manage the money without support. For the CDWs, this presented a dilemma for which there were no easy answers:

> The success of winning money with and for them bred its own dependencies…I haven't got an easy answer; I think it's really difficult.

The grants manager felt some of the most challenging problems arose after the initial award had been made, as groups often struggled with monitoring and record keeping:

> When it comes to the follow-on work, which is interim monitoring…they fail miserably on that.

However, this participant went on to question the assumption that all groups actually want substantial grants. In his experience the added responsibility that comes with larger funds can make groups fearful in spending their funds:

> [they are] frightened to death to spend the money in case I come back and say 'why have you spent that on that!

Tensions about fund-raising sometimes occurred between national charities and their affiliated self help groups, as most organisations required that groups undertook at least one fund-raising activity a year. Although most were keen to promote the mutual benefit and need for this activity, one participant did not want local groups to feel it was obligatory:

> I like the idea that we're important to them and that is why they do it, rather than me saying: "It's time".

4.3.5 Evaluation and accountability (see also 3.5)

At times, particularly when larger amounts were at stake, funding could lead to increased demands for accountability and evaluations of group activities. This was another area in which participants felt groups struggled. There was agreement that the target-focused statistical framework set by statutory authorities was inappropriate and unhelpful. One participant questioned the relevance of statistical evidence in this context and instead favoured members speaking directly to funders to substantiate impact:

> A lot of Trusts want statistical evidence…You could argue it's not as worthwhile as they think it is…It's changed their lives and…that's the proof isn't it?

However, most agreed that there were no easy answers to this issue, as alternative approaches are often not practical or possible:

> You can't go and be a fly on the wall in such intimate settings.

Finding appropriate ways of measuring impact were deemed necessary despite the challenges, as the currently favoured statistical approach can make members feel 'the system is at their back'. Participants highlighted that questionnaires are often not completed in a rigorous way due to members' health or social issues, yet there are insufficient resources to ensure each member participates in evaluation exercises.

The BAME coordinator felt that part of his role was to explain to groups why evaluation is necessary, along with helping them choose what outcomes to measure and how to carry this out:

> You have to first of all see where the people are and engage with them. How will they measure their own outcomes?...You can suggest to them and give them structures how they can measure it, like how many people are coming, how many

> people are getting other voluntary work, how many people are going to college, how many people are doing this, and then you educate them why we need to know these things.

4.4 Challenges for practitioners

4.4.1 Boundary-setting

A number of participants working closely with self help groups described how the work was often personally challenging by potentially exposing their own vulnerabilities. The demands upon them might take them out of their professional comfort zone and boundaries can become blurred. Several participants suggested the importance of establishing boundaries from the outset and learning to step back from the group at times:

> I think self help workers have to be very clear about the boundaries and I think if they're unclear you could get into all sorts of trouble…I think you need to give thought to that and be very clear with people.

> Even if the group isn't going 100% well, there's a limit to which you can direct it…sometimes you've got to leave it alone.

Blurred boundaries can often lead to a dependency on practitioner support. For example, one CDW struggled to reduce dependency when he found himself carrying out routine administrative tasks for a group over a long period of time:

> You get into helping, them resourcing, and there's just a whole field of dependency around that. I get angry at times when they say, "Now you need to be getting to grips with that" and me saying, "No, no, no, you need to do it!", and…three years on, five years on, you're looking and thinking, I'm still providing support.

Some participants offered strategies for minimising dependency, by avoiding becoming too 'friendly, friendly' with the group. One participant suggested avoiding attending group meetings as one way of reducing dependency, based on her experience of working in an organisation that specifically supports self help groups. However, she recognised this would not always be possible, as practitioners may be required to attend meetings regularly but here she suggested attending only part of the meeting enabling members to raise confidential matters in her absence. She also recommended wearing a uniform, if applicable, as a useful way of visually distinguishing the worker and reminding members that they are an outsider to the group.

4.4.2 The use of volunteers

Some participants had experience of using volunteers to support self help group activity, and felt they bring both opportunity and constraint. Many had reservations about the current policy emphasis on volunteering, arguing that volunteers cannot be a substitute

for paid staff. Volunteers, by their nature, come and go as their life changes direction, which inevitably impacts upon levels of commitment. The CDWs were concerned about the lack of accountability, as it can be hard to enforce duties or ways of working that unpaid volunteers do not like:

> That loss of contract that's inherent in paying someone a wage…. you can't manage stuff half so well if you're not paying people.

4.4.3 Group leadership (see also 3.4.3)

One participant spoke of the pressure on the coordinator of the group she supported. She said that he had a 'love-hate relationship with his role'. It is a common problem, she believes, that people who take the lead role in groups find it hard to delegate and share responsibility, partly because they fear they will lose some of the respect they gain from being leader, and partly perhaps because they may not feel others are up to the job. This means that they are not able to share the burden of running the group and may become under great pressure:

> He does find it very stressful and it is very stressful, and people don't necessarily step up to support him as much as they should, but he has almost carved that out for himself because the payoff is he gets a lot of recognition for that…He finds it quite difficult to share both the respect but also the jobs.

Instead this participant felt that groups need different people at the helm at different times, much like a business. At the start it is important to have 'the go-getters…who have the vision and the ambition and the energy, but when it comes to stabilising, you need the foot soldiers' who work to ensure the group carries on achieving its purpose of helping people.

4.4.4 Working in a context of public sector cuts

Many of the participants were aware that the changing political and economic context was likely to affect the development and sustainability of groups. Yet on the whole most were confident about the future for self help groups and felt there was the opportunity for positive change:

> I've never heard so many discussions between agencies and between professionals where people are saying, 'we've got to find a new way of doing things'…if we miss that opportunity and remain cap in hand looking to the state to finance us…we've just missed an absolutely brilliant opportunity to make something out of a crisis. I think the challenge is, for all of us, to kind of step outside our professional roles and be a human being…and say, 'oh well, let's just do something'.

> A self help group is the way for the future that will save money, that get people well.

Indeed the grants manager felt change was necessary as he felt in recent years groups had become too complacent and reliant upon easily available revenue sources for which they were able to apply 'year after year' without any real reflection on the purpose, progress or direction of the group. As these funding streams become scarcer educating groups about imaginative ways of raising funds will become an increasingly important task for agencies similar to his:

> So they've been a little bit complacent with the fact that they could live on grant funding, erm sadly now they've all got to be re-educated that you know funding is getting tighter, they've got to get back up on their own two feet and raise a little bit of funds themselves…and it is getting more and more difficult for groups to raise income themselves by having you know traditional jumble sales, and raffles and things.

5. Discussion

In considering the findings presented from Stage 1 of the research it is necessary to take into account that further stages will explore and examine these areas in greater detail. However the findings at this early stage provide interesting insights into the nature, characteristics and challenges facing the participating self help groups.

5.1 Definitions and classifications of self help groups

The groups that participated in this research illustrate the myriad configurations that self help groups can take in relation to form, focus and function. In the literature there has been a tendency to promote an ideal 'pure' type of self help group that is characterized by its informality, small size and member led ethos (Riessman, 1998). Early findings reveal a more complex picture with no easy categorization of group types possible. Groups with a very broad range of structures, sizes and methods saw themselves as fulfilling the traditional functions of a self help group, in their provision of, sometimes life-changing, support and knowledge. They restored hope, shared information on how to live well, brought people together in new, often close relationships and for some provided a renewed sense of purpose as they took on new responsibilities and roles. These benefits are in contrast to concerns that have been raised in the literature, which have suggested self help groups can encourage members to dwell on their illness or adopt a 'victim' mentality (Elsdon et al, 2000; Damen et al, 2000). Instead our findings indicate that due to the information-sharing and confidence-building processes in the groups, members became better informed about their situation and enabled to articulate their needs to professionals in a more assertive and constructive way. Many gained access to the services they need more effectively, were able to adopt healthier lifestyles and achieve greater wellbeing despite the challenges they face.

However the myriad forms self help groups take makes defining and classifying them problematic. The difficulties, as outlined in the introduction (see 1.2), exist in part because they often have numerous, concurrent aims and functions. Furthermore, some group members were not attached to the term 'self help' itself, even when this term formed part of the group name. Instead, 'peer' or 'support' group were two of the favoured terms to describe the groups. Yet although the term of 'self help' did not always fit comfortably with the groups the distinct ethos associated with self help groups, of shared experience, mutual support and member led tacitly emerged from the accounts. However even this was not without some grey areas as the groups often welcomed those who were indirectly experiencing the shared issue, such as family and friends.

Nonetheless despite these ongoing challenges with definition and classification it appears that these groups remain somehow distinct from other types of 'support' groups, such as a user or expert patient group. Yet this notion of an ideal 'pure' self help group did not adequately reflect the groups that participated in this research, as a number of groups were found to be larger in size, more formally organised and in some cases funded to provide services. Self help groups have been criticized for often lacking a community focus, preferring instead to address members' concerns in isolation from their social

surroundings (Bauman, 1999), yet our findings illustrate that a community, outward focus was a concern for a number of the participating groups. Perhaps most surprising was that formalisation and size did not necessarily lead to a loss of the intrinsic components of a self help ethos, as mutual support and a sense of closeness still occurred in these larger groups but would usually take place in smaller sub-groups.

Further discussions on definitions and classifications to pursue and capture an 'ideal' type of self help group may seem unnecessary. However, as echoed in the expert practitioner interviews (see chapter 4), clarity of the characteristics of self help groups is crucial so that those involved with supporting these groups understand and appreciate the ethos and purpose of these diverse, fluid groups. This will be particularly pertinent in the next Stages of this research, which involve developing guidelines for practitioners on how they can best support these groups. Therefore, as our findings indicate, although certain organisational forms may be desirable they are not vital as many groups were found to be not only surviving but also thriving with a variety of organisational forms and characteristics. Inevitably these differences are likely to mean that at different times of development and crisis particular types of support will be required. Yet these nuances have not always been fully recognized in the literature, as there has been a tendency to discuss the support needs of self help groups as a homogenous entity. Therefore without continuing examination of the potential diversity of these groups these complexities are likely to remain unacknowledged and unexplored.

5.2 Challenges

Even though the sample size of the participating groups was small, the in-depth interviews and discussions that were undertaken illuminate some potential interesting differences between the groups. One of the greatest challenges group coordinators faced, to some extent in Nottingham, but more so in Essex, was encouraging collective group involvement. This was an ongoing source of frustration with the coordinator role becoming burdensome at times for some due to a lack of collective involvement. Members often lacked confidence in their own ability, along with poor health, old age, cultural difference and lack of time and interest to take on collective responsibility for the running of the group. However these are preliminary findings that need further examination, particularly in comparison with the Nottingham sample where collective involvement was less of an issue and the reasons as to why are not fully understood as yet.

One possible explanation for these and other differences between the Nottingham and Essex groups may be linked to the presence of SHN in Nottingham. As an organisation that is well established in actively promoting and supporting self help groups the Nottingham groups were in a privileged position compared to those in Essex. This is an area that would merit further exploration to examine if the support and guidance groups from Nottingham received from SHN enabled them to manage and develop strategies to encourage collective involvement.

Another challenge identified by a few groups in Nottingham, but more so in Essex, was the frustration they felt in gaining respect and recognition from statutory services and professionals in the work they were doing. There was deemed to be active resistance from a range of professionals and practitioners in promoting and publicising the groups to potential new members. Clearly there is a need for further investigation as to whether professionals and practitioners in Essex may be more hesitant about promoting the value of self help groups to their potential clients and the possible advantage to groups in Nottingham arising from SHN raising the awareness and value of self help groups with professionals and practitioners.

Another area that requires further exploration is the benefits and tensions associated with groups being affiliated to larger charitable organisations, and reasons for seeking charitable status. Benefits associated with these options might include support and guidance on setting up and maintaining a self help group, along with a degree of status that might help in attracting funding. All groups, across the two sites, struggled with funding and this was an area where support and guidance were most highly valued, but those providing this support often found it to be most challenging. The expert practitioner participants who were working directly with self help groups struggled to give enough support without creating a risk of dependency.

Intrinsically linked with the challenge of securing funds, was the challenge of monitoring outcomes. The expert practitioner participants felt current requirements were not adequately capturing and representing the value and benefits to individuals attending self help groups. This issue needs to be explored further with self help groups, funding bodies and potential partners within health and social care.

The range of skills of those working directly with the groups were wide-ranging, and maintaining sensitive and respectful boundaries could be an ongoing struggle; further stages of the study will need to consider this. At this early stage the findings illustrate how crucial it is for practitioner support and guidance to be informed by an understanding of group members' aspirations regarding form, function and focus, and the nature of the support they want, as without which there is the potential for ill-informed and inappropriate 'support' to have negative effects.

5.3 Future developments

The current government vision of a 'Big Society' encourages individuals to be involved and responsible for their own wellbeing (Cabinet Office 2011) and this wellbeing agenda is of central importance in a range of policy and strategy initiatives in public and mental health (DH, 2011a; DH, 2011b). A number of studies (Kyrouz et al, 2002; Pistrang et al, 2008), the findings from which this research also supports, have shown that being part of a self help group often leads to improvements in individual wellbeing. Thus the potential for developing self help groups in the UK in the current economic and political landscape seems favorable. Indeed a small number of groups from this study, who had a strong community focus and who were providing services would appear to represent this new

political agenda. Therefore the opportunities in development and funding for these groups appear encouraging.

However, as funding streams become scarcer it is likely there will be a greater emphasis on outcomes and greater demand for monitoring and evaluation. The concern is that those groups which are more inward looking will struggle to meet these requirements, thereby potentially limiting their sustainability. These are issues to be aware of as we move into the next Stages of the study.

5.4 Areas for further examination

The following suggested areas would benefit from further exploration in the subsequent Stages of the research:

- Collective group involvement.
- Recognition from professionals / practitioners of the value of self help groups.
- Reasons for and benefits of groups choosing affiliation and charitable status.
- SHN and its impact on groups, particularly in relation to the above points.
- Funding, monitoring and evaluation issues.
- Strategies for practitioners to maintain boundaries and minimise group dependency.
- Issues for intermediary organisations such as CVS and SHN.
- Different support issues for BAME groups.

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