Self-Help Groups

Self-help groups for individuals who experience mental distress: Proceedings of a self-help group members' symposium and a review of selected literature

Autumn 2004
Poem

Strategy for Sharing
By
Malcolm Budd

Down to London on the train
Of self help discuss explain
Up to town is still trying
Big Ben for those aspiring

Cross the Thames at flooding tide
With bold Di who would not hide
And those who care are meeting
No one there of market fleeting

What we know all to explore
Just to share and not to score
Much to hear in just one day
We all have something to say

Sarah David with some flair
Keep some order with great care
And our day is flying past
Lunch is taken its no fast

Progress made in smaller groups
Someone there picks up the loops
And then we’re altogether
Firm views held without tether

All too soon come closing words
Mental health without absurds
A long journey back up north
The Pennine hills and Oakworth
Acknowledgements

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**Appendix I – Self-help group mapping exercise**

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Introduction

The work presented in this report reflects a collaboration between the Mental Health Foundation and Rethink. Findings from a symposium held for members of self-help groups for people who experience mental distress are presented together with selected findings from the self-help literature. The report includes also the results of a mapping exercise carried out by the Mental Health Foundation in December 2003, which sought to estimate the number of self-help groups in England for people who experience mental distress. This small programme of exploratory research is intended to inform further work by Rethink and the Mental Health Foundation into self-help.

Context

Both Rethink and the Mental Health Foundation have ongoing programmes of work into self-management. Rethink have published literature on self-management, provide facilitation skills training and are establishing self-management groups for people who experience psychosis and/or have a diagnosis of schizophrenia. The Mental Health Foundation’s ‘Strategies for Living’ programme has for the last 6½ years been interested in peoples own coping strategies for living with their mental distress. This work has included two user-led research projects, Sharon Matthew’s (2001) project which explored the empowering nature of user involvement groups and Jill Clarke’s and Angela Smith’s (2003) project into Self-help groups for people who self-harm. This project uncovered the benefits and difficulties of attending groups, and how groups maintain and sustain themselves through difficult periods. Additionally, secondary analysis of interviews from the original national ‘Strategies for Living’ research of South Asian women reinforces the importance of mutual aid and shared experience by showing the great value women find in attending groups with other women that have experiences similar to their own, (Hutnik & Wright, unpublished).

The Mental Health Foundation has been keen to build on this work, first by initiating a mapping exercise (Please see Appendix I) which sought to determine the number of self-help groups that exist for people that experience mental distress and/or use mental health services across England, as well as to find out about the basic characteristics of these groups. The work has also contributed to the development of a research proposal in partnership with Anglia Polytechnic University, which includes a more comprehensive review of the literature.

This work comes at a time when self-help is of growing interest to practitioners and policy makers. The NHS has developed a programme of expert patients to support others in learning self-management skills (www.expertpatients.nhs.uk). The National Institute for Mental Health in England, (NIMHE) has undertaken a literature review of self-help and the national Mental Health Research Network has a self-help interest sub-group. The focus of this work tends to be on clinical perspectives such as brief therapeutic interventions rather than on the service user perspective.

David Richards (2004), chair of the Mental Health Research Network, states that all perspectives are necessary to properly debate the role of self-help in modern healthcare. In this respect the Mental Health Research Network’s self-help interest sub-group now has a writing group that looks at user perspectives, and NIMHE have funded a consultative
event in the North East of England, being part organised by the University of Sheffield\textsuperscript{1}. This event was staged to find out how service users and survivors define self-help, and to find out what methods work for them. The symposium findings presented in this report are intended to complement this work and present a further account of what self-help means from the service user and survivor perspective.

\textsuperscript{1} For more information about this event being held on 2\textsuperscript{nd} July contact Rosemary Telford at the University of Sheffield on: 0114 222 0754/ r.telford@sheffield.ac.uk
Symposium and Literature Review Findings

The self-help group member symposium was held on the 1\textsuperscript{st} April 2004. This event was attended by individuals from across England who had responded to the Mental Health Foundation’s Mapping Exercise (Appendix I). The majority were members of self-help groups, some were also facilitators and a few were from organisations that had supported self-help groups. There were a total of 27 attendees. The day was structured around discussion groups, plenary sessions for feedback and comments, along with floor slots where 10 people were able to give five minute presentations describing their own experiences of being part of a group.

The main aim of the symposium was to talk together and learn from the experiences of being in self-help groups and to explore the following issues:

- What is a self-help group?
- Groups with or without facilitators
- What makes a ‘successful’ group?
- In what ways do groups fail?
- The positive and negative aspects of self help groups
- Joining and leaving a self-help group
- Independence of groups and relationships with statutory services

The project also aimed for the event to be open and inclusive whereby everyone’s voice could be heard and recorded. All attendees were asked to evaluate their satisfaction with the format of the symposium on a 5-point Likert scale. Of the 17 evaluation forms received 88% of the attendees were very happy with the way that the day had been organised.

The next section of the report is structured around the seven topics listed above. Findings from the symposium are presented and discussed in relation to the self-help literature.
What is a self-help group?

For the purposes of the Mental Health Foundation’s mapping exercise (please see Appendix I) the following definition was used:

"A self-help group is made up of people who have personal experience of a similar issue or life situation, either directly or through their family and friends. Sharing experiences enables them to give each other a unique quality of mutual support and to pool practical information and ways of coping. Groups are usually run by and for their members, although we know that some self-help groups may be facilitated by a paid or un-paid worker who may or may not have the same personal experience."

During the Symposium it was evident that people define groups in different ways. Sometimes groups had grown in size and had become small organizations in themselves, offering various services or training. Other groups were set up for the purpose of campaigning for change in the mental health system, and sometimes groups were established around a particular activity such as an art’s group. Though there were similarities in terms of what individuals might get from belonging to groups there were clear differences in the way groups were set up and organised.

In Wallcraft’s (2003) research examining the mental health service user movement in England, 300 local groups took part in the survey. Of these, 79% stated that their main group activity was self-help and social support, with 72% of their activities relating to consulting with decision makers and 69% being involvement in education and training. Initially, the symposium considered user groups and self-help groups as different entities, however it seems many groups have as their most common activity the provision of mutual support and practical advice, and see themselves as either a user group or as a self-help group with the definition varying according to how or where it is being used.

Research has explored the various ways in which groups might be defined. Professor T. Borkman (1997) who has written much on the subject of self-help groups in the US, states that there are three important ways in which groups differ, these are:

1) The extent to which they have developed an alternative organisational structure to the conventional bureaucracy.

2) The extent to which their goals are primarily ‘therapeutic’ to support members or to include advocacy goals.

3) The extent to which they co-operate with professionals and with mainstream services.

These differences fitted with the kinds of issues arising for group members who took part in the mapping exercise and symposium. There were various views on whether groups should get involved in campaigning. One person felt that groups had to evolve beyond the

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2 This definition is adapted from a definition in Self-help Nottingham, directory 2001. For further information on Self-help Nottingham contact Ormiston House, 32-36 Pelham Street, Nottingham, NG1 2EG, telephone no: 0115 911 1662.
therapeutic to survive, and there was much discussion about the relationships with statutory services and voluntary sector organizations. One individual attending the Symposium had come with a colleague from the local Trust. Their group and the Trust had brokered an agreement regarding the expectations of each other, which had formalised their relationship.

A Symposium discussion group examined the question, ‘what is a self-help group?’ and determined that each group would decide for itself. Discussions centered on what groups do, why they meet and how they are structured. Groups were described as having activities such as: self-help meetings; holding awareness days; providing speakers for events; giving training; taking members on trips; doing activities such as gardening or art; promoting equal opportunities and networking with statutory bodies. Groups therefore can be very broad in what they undertake to do. Some groups will always have an internal focus whereas other groups are interested or will become interested in effecting external change.

In Hatzidimitriadou’s (2002) research on the empowering nature of self-help groups, the research groups were characterized by their political ideology and the nature of their activities. Groups whose sole aim was the personal change of their members were classified as conservative groups, and those that stated their aim was to change or improve the mental health system were identified as radical. Those that did both were referred to as combined groups. Hatzidimitriadou used Emerick’s (1995) typology of groups according to their political ideology but also looked at group activities. Most research in this area examines a group’s helping mechanisms and the individual benefits accrued from group participation. Hatzidimitriadou’s research contributes new empirical data looking at the relationships between the ideology/typology of groups and their mechanisms. The findings from this research demonstrate that empowerment is at the very heart of a self-help group.

Groups with or without facilitators

Kurtz (2004) states that:

"self-help groups aim at effecting change and seldom have professional facilitators. Support groups meet for the purpose of giving emotional support and information to persons with a common problem and are often facilitated by professionals and linked to a social agency or larger formal organization"

There was much discussion at the symposium about whether groups with facilitators were self-help groups. There are also many groups calling themselves self-help groups that are affiliated to national mental health organizations such as the Manic Depression Fellowship, Hearing Voices Network and Depression Alliance. Jeremy Bacon, Self-help groups co-ordinator at the Manic Depression Fellowship3 (MDF), states that their self-help groups, though facilitated and linked to an organization, still tend to vary enormously in how they are organized and in their activities. The groups’ main interest is mutual support through shared experience but many will also become involved in local activities such as consultations with Health trusts and other decision making bodies. Also, facilitators of MDF

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3 Meeting held with Jeremy Bacon at MDF on 29 April 2004.
groups share the experience of the rest of the group, however this may also include being a carer as MDF groups can be open to people with a diagnosis of Manic Depression as well as their friends, families and relatives. Individual groups may determine their own membership with some groups being made up of only people with the diagnosis or direct experience of manic depression.

Clarke and Smith (2003) in their user-led research looking at self-help and support groups for people who self-harm also differentiate between self-help groups and support groups. In addition, they differentiate between support groups with paid facilitators and support groups with unpaid facilitators. They suggest that though support groups do have similar criteria to self-help groups there are more likely to be power differences between the members and the facilitators. Though in groups with unpaid facilitators the person in this role is more likely to share personal life experiences with members of the group (Oka & Borkman 2000 and Clarke & Smith 2003). Clarke and Smith defined self-help groups as ‘mutually supportive’ with no leader and where all of the group members were equally responsible for the smooth running of the group, (ibid, 2003). Interestingly however, their research findings identified groups failing or having difficulties due to the responsibilities falling on one or two group members, which can lead to ‘burn out’ for individuals (ibid, p19).

The Hearing Voices Network (HVN) provides a number of self-help/mutual aid groups. These groups are sometimes facilitated by a professional who is not necessarily someone who has heard voices themselves. Also, some groups can be attended by carers, relatives and friends of voice hearers. However, the HVN have just developed a charter defining groups affiliated and with full membership to the network which state clearly that a HVN group is not a treatment group with the aim being that the group will eventually become a user-run group4.

At the Symposium a HVN group member was challenged by other self-helpers about whether or not their group was a self-help group. The member of the hearing voices group felt very strongly that the group was indeed a self-help group and that the group members provided each other with mutual support in the same way that groups without professional facilitators might, and that the facilitators role was to enable this to happen.

Benedicte Carlsen (2003) in her research on professional support of self-help groups looked in detail at a self-help group for Chronic Fatigue Syndrome patients and states that it had been observed that the role of a professional group leader can change the power dynamics and the empowering quality of a group. However, it may well depend on the historic relationship between professionals in respect to the particular issue or concern.

The Hearing Voices Network was established as an alternative to the traditional medical model view of how to support and treat voice hearers. From its outset it has been a collaboration between professionals and voice hearers (Munn-Giddings & Borkman, to be published). This was due to the groundbreaking research of Professor Marius Romme who challenged traditional services and treatments for voice hearers. The HVN has promoted the importance of peer support and of accepting voices rather than suppressing them (ibid 2004). It is perhaps the positive professional involvement from the beginning

4 The Hearing Voices Network can be contacted by telephoning 0161 834 5768 for further details of their new Charter.
together with an alternative model that makes it possible for these groups to work with a professional facilitator.

In discussing how groups did or did not benefit from having a facilitator it was stated that it was important first to define the role of a facilitator and to see what a facilitator could bring to a mutual aid group. It was stated that a good facilitator ‘will make a group run by themselves’. A facilitator’s role is to be without opinions, to be considerate of group members, and to enable things to happen in a group. The symposium attendees agreed that good facilitator skills were seen as being very important and included: listening skills; being comfortable within the group; not being bossy; and someone who is able to empower the group.

An evaluation by Cella et al (1993) of a Community based Cancer Support group showed the description of the groups’ facilitator as: caring; involved; sensitive; understanding; accepting; aware; confident, active and fair. However, the same study showed that whilst facilitators were appreciated, peer support was the ingredient noted by participants as the most helpful aspect of the group.

One person at the symposium described a facilitator as a ‘calm caretaker’. It was stated that a facilitator was not a therapist, but was a strong person giving the group continuity. However others felt that there were other ways in which continuity could be achieved through group agreements (ground rules), structures and patterns and that these are ways in which groups can be run and sustained through mutual support with no facilitator.

Another person from an organisation that supports self-help groups that do use facilitators stated that it was important to have a facilitator to help groups feel safer and to help manage conflict should it arise. Facilitators of groups in their organisation did share the same experience as group members and this was seen to be important. It was also stated that training to be a group facilitator could be an empowering experience and a step forward in recovery for people who experience mental distress.

There were practical concerns about facilitated groups which related to what would happen if the facilitator wasn’t well or was on holiday, some people cited being in situations where groups had not ran because a facilitator wasn’t available, this was seen to be very detrimental to a group and its members. Another important attribute it was felt a facilitator would require was to be ‘well’ and to have some connection to the outside world.

During two of the floor spot presentations contrasting groups were described. A group that had adopted some of the 12 step programme structure that helped sustain the group and another group that belonged to the Self-Help Initiatives Project, SHIP, which is a user-led support organisation for self-help groups. SHIP groups do have facilitators who share the same experience as the group members and are there to help group members through giving positive feedback rather than advice. A group session was described in which some very distressing information was shared as an example of how safe members felt within the group.

It seems that in the research literature there is a divide in how self-help groups are defined between those that are facilitated and those that are made up only of members that share the same experience. This definition is not necessarily shared by group
members of different types of groups. Group members of facilitated groups can also define themselves as belonging to self-help groups.

- **What makes a successful group?**

Despite the differing views on what a self-help group is and the role of facilitators there were common views regarding a group’s success. It was felt that successful groups are ‘..ones where people can give something, contribute and feel valued’.

It was also agreed that ground rules or group agreements that are agreed and owned by the group are important in a group’s success. Many of the views given during the symposium discussion on the success of a group centered on the ownership of the group by its members. The importance of a self-help group compared to other more traditional services or therapy groups is that the members are active participants. However, some of the suggested reasons for a group’s success came down to the individuals that are in the group and certainly group dynamics have a part to play in the success of any group. ‘When the tide is high and the chips are down you need someone with persistence and determination’

Another person stated that successful groups have ‘good morale and someone who can foster that’. Clarke and Smith (2003) described groups that are often run by one or two members who take on the responsibility for ensuring that the group takes place. However, another criterion believed necessary for a successful group was having clear aims and objectives. The structure of a group is therefore seen as important in keeping a group going and in making it successful.

Other important criteria for a group’s success were:

- **Consistent attendance** - this included the idea that a group was successful if even 2 people were attending regularly.
- **Accessible to all** – ensuring that group members were aware of any barriers to attending and had taken steps to counter these.
- **Friendly and welcoming**, with tolerant and respectful members.
- **Practical issues** – e.g. the venue was an important contributor.
- **Funding** – e.g. that there is enough funding to meet the group’s requirements.
- **Visibility** - steps to make sure the public and services know about the group.
- **Having fun** in groups was also seen as important.

In Clarke and Smith’s (2003) study, being linked to other groups was deemed important for a group to succeed. The Manic Depression Fellowship’s regional network meetings for group facilitators and members have proved successful for groups forging links with other nearby groups and in terms of sharing learning and good practice. In addition, the meetings allow groups to inform the national organisation on how they can be supported, and for the national organisation to disseminate learning from groups to the whole network (Jeremy Bacon, 2004).

Certainly many of the attendees at the symposium felt it very important to have an opportunity to come together with other self-helpers and share knowledge and learning. Many people asked when we would be holding the next event. In the mapping exercise 125 people had expressed an interest in attending an event with other self-helpers.
In the evaluation for the self-help event one person stated, ‘when’s the next one’ and another said how rare it was to have the opportunity to get together with other people involved in self-help groups.

- **In what ways do groups fail?**

At the symposium there was discussion around whether or not we should use the term failure. It was stated that groups succeed when they are not afraid to make mistakes and that mistakes are learning experiences.

However it was also stated that there were ways in which groups could run into difficulties:

(i). Issues around facilitation
- If there was no-one available to take responsibility of practical issues – someone stated a lack of a facilitator as an example, however this is not straightforward as many people did not believe in the necessity of a facilitator.
- If the facilitator isn’t supported this can lead to facilitator burn out and the end of a group.

(ii). Impact of the relationship with other services
- Groups can fail when professionals do not have faith in the group and therefore do not refer individuals.
- Groups can fail if services end up running them rather than the group members.

(iii) Issues relating to group members
- Difficulties can emerge if there are not clear enough boundaries and there is contact outside of the group that is difficult for the individuals involved – this can lead to groups feeling unsafe.
- Groups can fail if there is a lack of a core of motivated individuals attending the group.
- Groups can fail when there are no ground rules.
- There is a lack of motivation within the group to support its continuation.
- No members due to a lack of research of target group.

(iv) Other issues
- External difficulties such as funding difficulties or pressure to have an evaluation.

- **The positive and negative aspects of Self-help Groups**

The symposium also discussed the positive and negative aspects of self-help groups – asking how people benefitted from going to a self-help group and what could make attendance at groups difficult?

Benefits to individuals of attending self-help groups have become fairly well documented, although most of the literature regarding self-help groups still comes from North America and professionals can still seem reluctant to recommend or refer individuals to groups,
(Borkman & Munn-Giddings, 2004). Yet the most often mentioned benefits to
individuals are reduced isolation; improved self-esteem; improved confidence; receipt of
practical information and support; feeling accepted and learning new skills and coping
strategies, (ibid).

In Clarke and Smith’s (2003) research they describe individuals feeling better about
themselves and gaining self-worth because of the help that they were able to give to
others. In Roberts et al (1990) they describe the ‘helper-therapy’ principle that explains
the process where helping others has a therapeutic effect for the helper. Self-help groups
provide an opportunity for individuals whose abilities and strengths have often been lost
or disempowered to use their strengths and abilities and take on new roles and
responsibilities in a safe environment. Roberts et al’s (1990) research provided empirical
support for the ‘helper-therapy’ principle by showing that participants in their study did
display improvements on the scales they used to indicate psychological and social
functioning. Self-helpers may feel better about themselves because their skills are being
recognized, they are active participants in their group rather than recipients of a service,
(Clarke & Smith, 2004) and also through offering help to someone who needs it also
affirms our value, as it makes us feel worthwhile and wanted (Roberts et al,1990).

Hatzidimitriadou’s (2002) research shows that members of self-help groups feel more
empowered through their roles within their groups. This empowerment works on an
individual level but it also operates on a collective level with group members in some types
of groups feeling more in control of their lives through community activism. Group
members feel that they have some actual power over social change whereas mental
health service users are generally seen to be a disempowered group without community
power. More often service users are seen as being discriminated against and stigmatized
by their ‘madness’. This research shows that belonging to self-help groups can enable
people to not only feel better on an individual basis but more socially included with more
community power. Munn-Giddings and Borkman (2004) also describe the collective
benefits of belonging to a self-help/mutual aid group: broader world view; collective
perspective and mobilization for social change or service innovation; opportunity to
influence services; critiques of professional practices; innovative relations with the mental
health system; alternative ways to get help and deconstruction/critique of medical
diagnosis or condition.

Wallcraft’s (2003) research on the user movement further reinforces the benefits of self-
help groups beyond the individual, in addition to showing that there are enough
commonalities in beliefs and understandings between groups to constitute a movement.

The symposium members highlighted other benefits that they had found in attending
groups such as:

- Increased mental creativity.
- Groups provide hope through seeing other people in the group that are at different
  places in their journeys.
- Groups have an important role to play in showing that experiences don’t have to be
  pathological.
There were many comments relating to making friends, reducing isolation, giving a reason to go out of the house, sharing experiences and helping find ways to look at things differently.

Clarke and Smith’s (2003) study found difficulties that occurred for individuals in groups as well as exploring difficulties for groups. They found that an issue for almost half of the women in their research was ‘worrying about others’. The women found they were effected by other people’s distress within the group and this would be triggered by someone not coming to the group for a couple of weeks or by their distress during a meeting. At the symposium it was stated that it is problematic in a group if everyone is distressed at the same time. In both Clarke and Smith’s (2003) research and at the symposium ‘fitting into a group’ was mentioned as a problem for some individuals since not everyone will find the group they attend suits them. It was mentioned also that groups can be cliquey.

Jeremy Bacon from the Manic Depression Fellowship stated that at regional network meetings for group facilitators and members many people had raised the issue of first joining a group as being very difficult. Groups had responded to this in different ways, he described one group that delegates someone to have the responsibility of greeting new members and bringing them into the group. Other groups encourage new members to arrive 10-15 minutes before the rest of the group so that they are already there and have been settled into the venue.

The location of the group was important and in Clarke and Smith’s study some respondents mentioned finding the location difficult either due to mobility difficulties or because of having to travel from another town to attend the group.

At the Symposium difficulties around the dynamics within the group were discussed. Difficulties occurred when there were people in groups who were very dominant or held very strong opinions. Another person stated that many people with mental health problems can find it difficult to have group interaction. Both these difficulties can be helped by good group agreements or through a strong group structure or facilitator.

The Symposium also considered whether there were inevitable difficulties in attending a group. The discussion centred around issues of group dynamics, which may always be changing as new members join and others leave. However, generally it was felt that there were inevitabilities of being in groups but that these weren’t necessarily negatives. Tuckerman’s model of group development was discussed and there was the understanding that groups go through various stages – forming, storming, norming, performing, and mourning. These stages may also move backwards and forwards, especially when group members come and go (Tuckerman, 1965)

As previously mentioned it was the important use of group agreements or ground rules that were returned to as a way of helping groups deal with any difficult times. In addition, feelings of ownership in the group were viewed as very important to help a group keep going. If all the members feel that they have a stake in the group then they will have a positive impact on how the group sustains itself and how difficulties are managed.

Richardson’s (2003) research on self-help groups, ‘Subjectivity in Therapeutic Space – the social dynamics of mental health self-help groups’ states that within the groups that she
studied there was little evaluation and feedback, and limitations as well as benefits were evident. Problems occurred in groups that were long standing, as they might sometimes be described as stagnant and in fact in groups where there were difficulties and challenges there was least movement towards possible change. In addition, the research raises a question about how far a self-help group can go towards providing support to an individual if a group is meeting only on a monthly basis.

The groups that were part of Richardson’s study (2003) were MDF groups meeting on a monthly basis and Richardson suggests that people may have difficult periods between meetings where they are not supported by the group. One of the groups in the study did provide external support outside of group times to members. Also the very nature of groups empowering individuals may mean that even when members are experiencing distress or difficult periods their ways of coping with periods in their lives may be different due to the influence of attending the group (Hatzidimitriadou, 2002).

Joining and leaving groups

Groups are often started by motivated individuals who are searching for others who have experienced similar issues. Sometimes groups are started because of national organisations supporting individuals to start up groups, such as the MDF, Depression Alliance (DA) and the Hearing Voices Network (HVN). In the Mental Health Foundation’s mapping exercise almost one third of respondents were founding members of their group.

There are a growing number of organisations around the country that are offering support to those wishing to start self-help groups, these are either independent organisations such as Self-help Nottingham or have been set up by the local Health Authority to support the growing number of groups that are being established in all areas of healthcare.

However finding a group is not necessarily easy and in the mapping exercise 72% of respondents wanted to be part of a national directory on self-help groups. Although maintaining a directory on an ever changing sector like self-help groups would be a very difficult undertaking.

Perhaps surprisingly, considering evidence to the contrary, the next highest proportion of respondents in the mapping exercise (Appendix I), found out about the group that they were attending through a mental health or social care professional. In Richardson’s (2003) study the question is raised as to whether doctors or psychiatrists should be referring individuals to self-help groups and asks if self-help and self-management should indeed become part of formal treatment of Manic Depression and other psychiatric illnesses. It was suggested at the Symposium that people are more likely to attend groups or stay attending if they choose themselves to attend the group and that the very nature of self-help groups is their independence from services and self-empowering nature. This is only anecdotal and there is little research evidence to suggest that those who are referred to groups by health care or social care professionals will not find attending groups equally rewarding. However there are certainly questions to be raised about where someone is in their ‘journey’ when they attend a group, it may be very difficult for someone in severe distress to attend a group independently. There are sometimes groups in psychiatric settings and there are more and more groups on-line, which may make it
easier for someone to ‘attend’ a group at more difficult periods of their lives. However, there is no research in the UK showing what gives people the impetus to join groups.

Members at the symposium did describe being nervous on first joining groups and as previously mentioned this was an issue raised at MDF regional network meetings on how groups might make it easier for new members to join (Jeremy Bacon interview, 2004).

Most groups are open and on-going so that members can come and go. One person at the symposium described being part of a group for more than 30 years, however some groups want people to move on when they feel well to free up space for new members. Members may choose to leave when they feel they no longer need the group any more, or as one person states in Richardson’s (2003) research when they are ‘saturated’ due to covering the same issues many times.

At the symposium there was a debate about people leaving groups when they felt better. Many people felt that group members owed the group something. It was felt that members should put something back into the group and that members leaving could be demoralizing for other group members. One of the respondents in Richardson’s (2003) research stated that it was uplifting when he felt depressed to hear positive stories at the group, showing the value of a group offering hope to its members.

In Clarke and Smith’s (2003) study, respondents that were no longer in groups gave their reasons for leaving. Two people had moved area, one person stated the group had closed down and one person stated that they no longer needed the group. However, for four people their group had felt ‘unsafe’ and three people had stated that the group had triggered their self-harm, although for most people their self-harm was reduced or stopped through attending a group. Another person stated that the issues were too difficult. Respondents were able to indicate more than one reason for leaving a group and in all only 11 people no longer attended a group. Richardson’s (2003) study provides much detail about creating safe spaces and the importance of safety in creating a therapeutic space. Richardson’s research suggests that safety is created through a number of factors:

- Being with other ‘sufferers’
- Freedom of expression
- Ground rules establishing confidentiality
- Sensitivity
- The group’s inclusive nature
- The absence of professionals
(Richardson, 2003, p30-31)

It was stated also at the symposium that rather than expect people to move on from groups to make room for new members groups could become two groups if they get too large.

- Independence of groups

In Wallcraft’s (2003) study of the user movement in England independence is cited as a major controversy for the movement. It is seen by some that closer working with government and statutory services means compromising the autonomy and independence of the movement whilst others see this as a way to appropriate real change. The very
nature of self-help groups is that they are about ‘self-help’, they are an alternative to the treatments and therapies offered by mainstream statutory and voluntary services. They can be used alongside mainstream health care or individuals can choose only to be a part of their self-help group. Certainly attending a self-help group has been shown to reduce access to mainstream services, and where users still use services they may feel more empowered to do so.

However, it is not so straightforward as to say that self-help groups should have no contact with professionals or statutory services. Sometimes it is professionals that have helped to set up self-help groups and in Hearing Voices groups professionals may indeed facilitate meetings. Statutory services can be seen as useful for funding self-help groups, although this can bring implications for the requirements of the groups. One person that attended the symposium stated that their group had part funding from their statutory services for user involvement and a lottery grant for the recovery part of their work. Others stated that relationships can be helpful if they are equal but sometimes professionals may become exploitative in their demands of groups. One person gave the example of the local Trust not being prepared to pay for training they were requesting from the group members.

It was stated that there is often conflict in the relationship between statutory services and self-help groups. Statutory services are bound by legalities such as risk management and have hierarchies and bureaucracies whereas self-help groups operate on egalitarian terms without these concerns. It was agreed that statutory services can be useful in providing self-help groups with publicity, although again there can be reluctance by professionals to refer people to groups especially if they haven’t attended a group and do not know what goes on there.

The symposium members discussed the benefits of being linked to a network through a voluntary sector organisation. These were around the support that could be received from the national organisation, such as financial help with rents, using a national organisation’s logo may help get funding, national organisations have good help lines and information resources, there are also opportunities for training and support when groups run into difficulties, and links with other groups. Certainly one of the recommendations from Clarke and Smith’s (2003) study on self-help groups for people who self-harm was that there was a need for a ‘network of groups’ so that support could be gained during difficult times and for sharing good practice. This research also cites the importance of professionals better understanding the benefits of self-help groups. Research by Adamsen and Rasmussen (2001) states that the time has come for healthcare professionals to look at the opportunities for consultative working with self-help groups and to move to debates which are beyond individual orientated treatment and care.

➢ Conclusion

Self-help groups are vital in the support that they provide for people who experience mental distress. Those people that attend groups often cite them as a life-line. Through telling their stories and sharing their experiences individual group members feel accepted and no longer alone with their distress and experience. As active participants in their
group and therefore their own well-being group members often feel more empowered as individuals and as collectives within their local communities.

This report shows that there are many similarities between groups, but it also shows that there are many differences and groups may define themselves in various ways and may be organized in different ways.

The symposium was a rare opportunity to bring together people who attend groups and also experience mental distress. Many of the attendees at the event wanted to know when the next event would be and greatly valued the opportunity to meet with others who attended or facilitated self-help groups.

It was clear that, as well as the need for more research in the UK about the value and function of self-help groups, there was also a need for more opportunities for shared learning and networks for members of groups to develop. There is also a need to pull together a more in-depth review of the literature in the field of self-help groups and mental health. It seems vital that NIMHE and the national Mental Health Research Network seeks opportunities to support hearing about users’ perspectives and experiences of self-help groups and mutual aid. To take this forward the Mental Health Foundation in partnership with Anglia Polytechnic University is currently developing a proposal for a two-year research project which would include shared learning and the development of a good practice in self-help groups training module. Meanwhile Rethink are continuing their work on self-management support groups with a programme of pilot groups which will be independently evaluated in terms of process and outcome.

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APPENDIX I
Self-help Groups Mapping Exercise

Introduction

➢ Context and Aims of the Study

The self-help and mutual aid movement for people with mental health problems has been a growing movement since the 1980’s (Wallcraft, 2003), within which individuals give support to other individuals in similar circumstances, having experienced similar issues/concerns themselves. It is difficult to estimate the number of self-help groups in the country as there is no national co-ordinating centre, because the groups are mainly independent of mental health services, and because many groups come and go.

The aim of this study was to survey self-help groups that exist for mental health service users or people who experience mental distress in England. Specifically, the study sought to find out what the basic characteristics of these self-help groups are. The study placed particular focus on self-help group members who have or had experienced personal mental health problems.

➢ Defining Self-help Groups

For the purpose of this study self-help groups and mutual aid groups were defined using the following explanation:

“A self-help group is made up of people who have personal experience of a similar issue or life situation, either directly or through their family and friends. Sharing experiences enables them to give each other a unique quality of mutual support and to pool practical information and ways of coping. Groups are usually run by and for their members⁶, although we know that some self-help groups may be facilitated by a paid or un-paid worker who may or may not have the same personal experience”.

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⁶ This definition is adapted from a definition in Self-help Nottingham, directory 2001. For further information on Self-help Nottingham contact Ormiston House, 32-36 Pelham Street, Nottingham, NG1 2EG, telephone no: 0115 911 1662.
Methodology

➢ Study Design

The study used a cross-sectional questionnaire based survey design. The geographical coverage of the survey was England only.

➢ Distribution of Questionnaire

Approximately 6000 flyers advertising the survey were distributed across England. The flyers requested that members of self-help groups contact the Mental Health Foundation if they were interested in completing a questionnaire on self-help groups.

The following are the mailing lists used to distribute the flyers:
- 1500 were sent to the Strategies for Living mailing list (England only)
- 1500 were sent to the – Mindlink mailing list
- 600 were sent to the – Part mailing to Diverse minds
- 1500 were sent to the – Hearing Voices and Sharing Voices Network e-mail list.
- 300 were sent to local CVS organisations around England via e-mail
- 600 were sent to Rethink’s mailing list.

In addition the survey was also advertised through the Mental Health Foundation’s 1 in 4 e-mail forum website (http://www.mentalhealth.org.uk)

It is apparent that many flyers were distributed onwards from their original recipient.

➢ Participants

There were 183 completed questionnaires. Thus, the response rate was approximately 3%. Various individuals who had responded to the survey were from self-help groups that dealt with shared experiences relating to carers of people with mental health problems and carers of people with Asperger’s Syndrome. These questionnaires were not included in the analysis and write-up. However, it does show that self-help and mutual aid is a wide movement supporting people with a range of experiences within society. Out of the 183 completed questionnaires, 92% of respondents to the survey stated that they were members of self-help groups. Five percent of the respondents stated that they were facilitators of groups who did not include themselves in the membership, or were from organisations that support self-help groups. In addition, 3.3% of respondents did not answer this question.

There are a number of self-help groups set up in England already well supported through networks by mental health organisations. Some of the respondents from the survey are from groups affiliated to the following organisations:

- The Manic Depression Fellowship has more than 100 groups.
- The Depression Alliance have more than 60 groups
- The Hearing Voices Network have more than 80 groups
- The Eating Disorder Association has 67 groups.
- The Self-harm Network has listings of self-help groups.
\textbf{Results}

The questionnaire covered a variety of topics with regard to self-help groups. The first section aimed to establish the basic characteristics of self-help groups. The following topics were covered:

- Group Facilitators (i.e. did the group have one and was this individual paid?)
- Types of shared experiences
- Size of the group
- Membership of the group (i.e. open/closed membership; gender; age group; race/ethnicity)

Other topics that were covered in the questionnaire included the geographical location of the self-help group; how people are referred to/get in contact with the group; what types of external help there is for their group; and their views on networking and attending a symposium for self-help groups.

\textbf{Characteristics of Self Help Groups}

\textbf{Group Facilitator}

The questionnaire asked people whether their group had someone specifically employed to facilitate the group. Out of the 183 respondents 53.6\% stated that they had a facilitator; 41.5\% did not and 4.9\% failed to respond.

In addition, 64.5\% reported that they had some type of facilitator, whether it be someone specifically employed to facilitate the group and/or a group member who had emerged or been appointed as the facilitator.

Participants were also asked whether or not the facilitator was paid or unpaid. Thirty one percent stated that their facilitator was paid, 17\% stated that they were unpaid, 7\% had both paid and unpaid facilitators and 0.5\% failed to respond. Around 9\% of respondents that stated they did not have an official facilitator, responded that their facilitator was unpaid. It could be assumed that this means the unpaid facilitator is a member of the group.

It is evident that the majority of respondents had a facilitator that had been specifically employed. In addition, the majority of these facilitators were paid. It is interesting to note that a moderate proportion of respondents belonged to a group that did not have a specifically employed facilitator but instead had a group member as their facilitator, and that this group member had been appointed by the group or had emerged as the group leader.

\textbf{Shared experience}

The questionnaire asked respondents what the shared experience of their group was. It is evident that there was a range of different experiences shared in groups.
Just over one third of respondents (36%) were from groups whose shared experience was described as: ‘mental distress’; ‘general mental health’; ‘mental illness of any nature’; mental health problems; and other definitions which brought together a range of experiences of mental and emotional distress. A small percentage of respondents (6.6%) brought a variety of different topics to the groups such as: mental health and nutrition; mental health and spirituality; post natal depression; young people and mental distress; friends and relatives of people who had committed suicide; homelessness; loneliness associated with parenting young children. Fewer than 10% of respondents did not state the type of shared experiences in their group.

The remaining respondents were from groups set up around more specific experiences. Table 1 shows the percentage of respondents belonging to specific groups of shared experiences.

<table>
<thead>
<tr>
<th>Type of Shared Experience</th>
<th>Percentage (N = 183)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>9.8</td>
</tr>
<tr>
<td>Manic depression (bi-polar disorder)</td>
<td>9.3</td>
</tr>
<tr>
<td>Depression</td>
<td>9.3</td>
</tr>
<tr>
<td>Psychosis (incl. Delusions/hallucinations)</td>
<td>5.5</td>
</tr>
<tr>
<td>Borderline Personality Disorder</td>
<td>2.7</td>
</tr>
<tr>
<td>Abuse</td>
<td>2.7</td>
</tr>
<tr>
<td>Self Harm</td>
<td>2.7</td>
</tr>
<tr>
<td>Mental Distress &amp; their carers</td>
<td>2.2</td>
</tr>
<tr>
<td>Alcohol &amp; Drug abuse</td>
<td>1.6</td>
</tr>
<tr>
<td>Sexuality</td>
<td>1.1</td>
</tr>
<tr>
<td>Minority Ethnics experiencing mental distress</td>
<td>1.1</td>
</tr>
<tr>
<td>Eating Disorder</td>
<td>1.1</td>
</tr>
</tbody>
</table>

*Table 1: Percentage of respondents belonging to specific group of shared experiences*

It is evident that the majority of respondents belonged to self-help groups that dealt with a wide range of mental health problems and served as sharing more general experiences of mental health. The most common specific experiences that groups shared was that of anxiety and depression. Psychosis was the next most common shared experience, then experiences relating to borderline personality disorder, abuse, self-harm and mental distress, and carers. The least most common shared experiences were those of alcohol
and drug abuse, sexuality, individuals from minority ethnic groups who experience mental distress and eating disorders.

• **Size of groups**

The questionnaire asked how many active members were involved in each group Table 2 represents the percentage of respondent’s belonging to different sized self-help groups.

<table>
<thead>
<tr>
<th>Group Size</th>
<th>Percentage (N = 183)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>14.2</td>
</tr>
<tr>
<td>5-10</td>
<td>28.2</td>
</tr>
<tr>
<td>10-15</td>
<td>16.4</td>
</tr>
<tr>
<td>15-20</td>
<td>10.4</td>
</tr>
<tr>
<td>More than 20</td>
<td>20.2</td>
</tr>
<tr>
<td>Varied</td>
<td>2.2</td>
</tr>
<tr>
<td>Did not respond</td>
<td>10.4</td>
</tr>
</tbody>
</table>

Table 2

‘Percentage of respondents belonging to different sized self-help groups’

It is evident that the majority of respondents belonged to moderately sized self-help groups (i.e., between 5-10 members), with the next most common group size being over 20 members. Group sizes less than 5 or between 10-20 members were less common.

• **Membership of groups**

The survey investigated group membership with regard to whether the group was open or closed (i.e. able to take on new members), gender, age or racially specific.

It was evident that the majority of respondents (87.4%) belonged to self-help groups that had open membership. Some of these groups had a waiting list, or they wanted to meet a new member before the group is willing to ask them to join the group, with other groups only willing to take on new members who had been referred to them. Around 10% of respondents stated that they belonged to groups that were not open to new members and 2.7% did not respond to this question.

With regard to whether group membership was based on gender, the majority of respondents (79.2%) stated that they belonged to mixed gender groups. Seven percent of respondents stated that they belonged to women’s only groups and 2.7% belonged to
men only groups (9.8% of respondents did not answer this question). With regard to whether group membership was age specific 86.3% responded that their group was not based on age, although additional comments showed that respondents were describing groups for people of an adult age. A very large proportion (92%) of respondents stated that the group they belonged to was not aimed at people from a particular racial or ethnic background. Only 3.8% of respondents stated that their group was aimed at specific racial/ethnic groups and the majority of these groups were aimed at the Asian population.

- **Location of respondents**

The questionnaire asked respondents about the location of their group. The majority of respondents (68.3%) stated that their group was located within a city or town, 27.3% stated that their group was located outside of a town/city, 4.4% did not respond to this question. The survey reached people across England. Table 3 shows the percentage of respondents by geographical location.

<table>
<thead>
<tr>
<th>Geographical Location</th>
<th>Percentage of Respondents N = 183</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Midlands</td>
<td>14.8</td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td>14.2</td>
</tr>
<tr>
<td>London &amp; Greater London</td>
<td>14.2</td>
</tr>
<tr>
<td>South West</td>
<td>12.6</td>
</tr>
<tr>
<td>South East</td>
<td>9.8</td>
</tr>
<tr>
<td>East of England</td>
<td>7.7</td>
</tr>
<tr>
<td>North East</td>
<td>4.9</td>
</tr>
<tr>
<td>West Midlands</td>
<td>4.4</td>
</tr>
<tr>
<td>Did not respond</td>
<td>5.5</td>
</tr>
</tbody>
</table>

*Table 3 ‘Percentage of respondents by geographical location’*

It is evident that the majority of respondents were located in the East Midlands, Yorkshire and the Humber as well as London and greater London. A moderate proportion where located in the South West and East as well as the East of England. The least proportion of respondents where located in the North East and West Midlands.
• **How do people find groups?**

The next section of the questionnaire asked respondents how they found their self-help group, Table 4 represents the means by which the respondents found their group.

<table>
<thead>
<tr>
<th>Means of Finding Self-Help Group</th>
<th>Percentage of Respondents N = 183</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent is the Founder of the group</td>
<td>24</td>
</tr>
<tr>
<td>mental health professional</td>
<td>13.1</td>
</tr>
<tr>
<td>Word of Mouth</td>
<td>9.8</td>
</tr>
<tr>
<td>Mental health organisation</td>
<td>6</td>
</tr>
<tr>
<td>GP or leaflet at GP Surgery</td>
<td>5</td>
</tr>
<tr>
<td>Organisation that aims to support self-help groups</td>
<td>4.5</td>
</tr>
<tr>
<td>Hospital/day centre</td>
<td>2.7</td>
</tr>
<tr>
<td>Resource Centre specific to their needs</td>
<td>2.7</td>
</tr>
<tr>
<td>From an article</td>
<td>1.1</td>
</tr>
<tr>
<td>Searching Directories</td>
<td>2.2</td>
</tr>
<tr>
<td>Internet</td>
<td>1.1</td>
</tr>
<tr>
<td>Their group had evolved out of another group</td>
<td>2.2</td>
</tr>
<tr>
<td>Did not respond</td>
<td>14.8</td>
</tr>
</tbody>
</table>

*Table 4: Percentage of respondents finding their self-help group by specific means’*

It is interesting to find that the majority of respondents where the founder of their self-help group. The next most common means of finding a group was through the respondent’s mental health professional worker, then by word of mouth. The least common methods of finding a self-help group are through the internet, searching directories, resource centre and hospital/day centres.
• **Help for Self-help groups**

The survey wanted to establish whether any of the respondents knew of organisations in their locality that had been established specifically to help self-help groups. A moderate proportion of respondents (43.2%) stated that there was a local organisation that supported them, however they were not necessarily set up specifically to help self-help groups. Many of these organisations were local mental health charities, sometimes national charities were mentioned as were local Council for voluntary Sector. However, a number of areas did have organisations set up that were there to work with self-help groups. Many of these organisations have been proactive in ensuring groups heard about the mapping exercise and self-help group members’ symposium. Those organisations supporting groups are particularly keen to form links with other supporting agencies, and there could be much opportunity for shared learning.

• **Networks, future opportunities**

Finally, the survey asked respondents if they would be interested in attending an event for members of self-help groups. Sixty-eight percent of respondents stated they would like to attend such an event with a further 6% stating that they might be interested. Twenty-two percent of respondents were not interested in attending this event and 3.8% of respondents did not answer the question.

The self-help symposium was held on 1st April 2004 and 30 self-help group members attended

Self-help group members seemed keen to ensure people knew of their group’s existence and of the importance and value of self-help groups. Seventy-three percent of the survey’s respondents wanted their group to be able to be advertised in a national directory, though the maintenance of such a directory with groups coming and going all the time would be fairly difficult. Another 61.2% of the respondents in the survey were keen for their group to be part of a research project about self-help groups, with 9.3% of respondents stating that they might be interested if their group agreed.

**Conclusion**

It is evident from the survey that the majority of respondents belong to a self-help group that has a specifically employed facilitator. In the majority of these cases the employed facilitator is paid. A moderate proportion of respondents self-help groups did not have a specifically employed facilitator but never the less they had a group facilitator. This facilitator is most likely a group member who either has been appointed by the group or has emerged as the group leader.

The majority of respondents stated that their self-help group dealt with shared experiences of a general nature (i.e. general mental distress). With regard to specific shared experiences the most common was that of depression and anxiety, with a moderate proportion dealing with issues of psychosis. With regard to group size the majority of respondents stated that their self-help group is between 5 and 10 members,
the next most common group size was over 20 members. The least common group size was under 5 members and between 10-20 members.

With regard to group membership, the majority of respondents stated that their self-help group was open to new members, they are of mixed gender and not age or race/ethnicity specific. It is interesting to note that for those groups that were gender specific, there is a higher proportion of female self-help groups over male.

The majority of respondents belonged to a self-help group in a city/town, with the majority of respondents’ groups being based in the East Midlands, Yorkshire, and in London (including Greater London). The majority of the respondents were the founder of their self-help group and a moderate proportion of respondents stated that they heard of their group from another person (i.e. friend) or from a health professional. It is interesting to note that the less common methods of finding out about self-help groups were from advertising in health organisations or over the internet. Finally, the survey established that the majority of respondents’ self-help groups had support from other organisations locally and some nationally.

In conclusion, the survey has successfully established the basic characteristics of self-helps groups within England. The next step from this project would be to establish how self-help functions within the wider context of mental health and what benefits self-help groups have on statutory services. It would be crucial to examine the effectiveness of self-help groups in comparison to other types of mental health treatments such as medication or specific types of therapies. It would also be beneficial to examine what specific support self-help groups require from external sources in order to function better in terms of desired beneficial outcomes for the group members. Thus, these issues should be incorporated into the next step in research on self-help groups.

Reference