selfhelp
nottingham & nottinghamshire

Putting self help into practice

A guide to working with self help groups for practitioners

Guide devised from

ESTEEM

Effective Support for Self Help/ Mutual aid groups study 2013

BIG IDEAS FOR THE FUTURE!

Anglia Ruskin University
Cambridge Chelmsford Peterborough

BIG LOTTERY FUND
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Empowering you to support groups
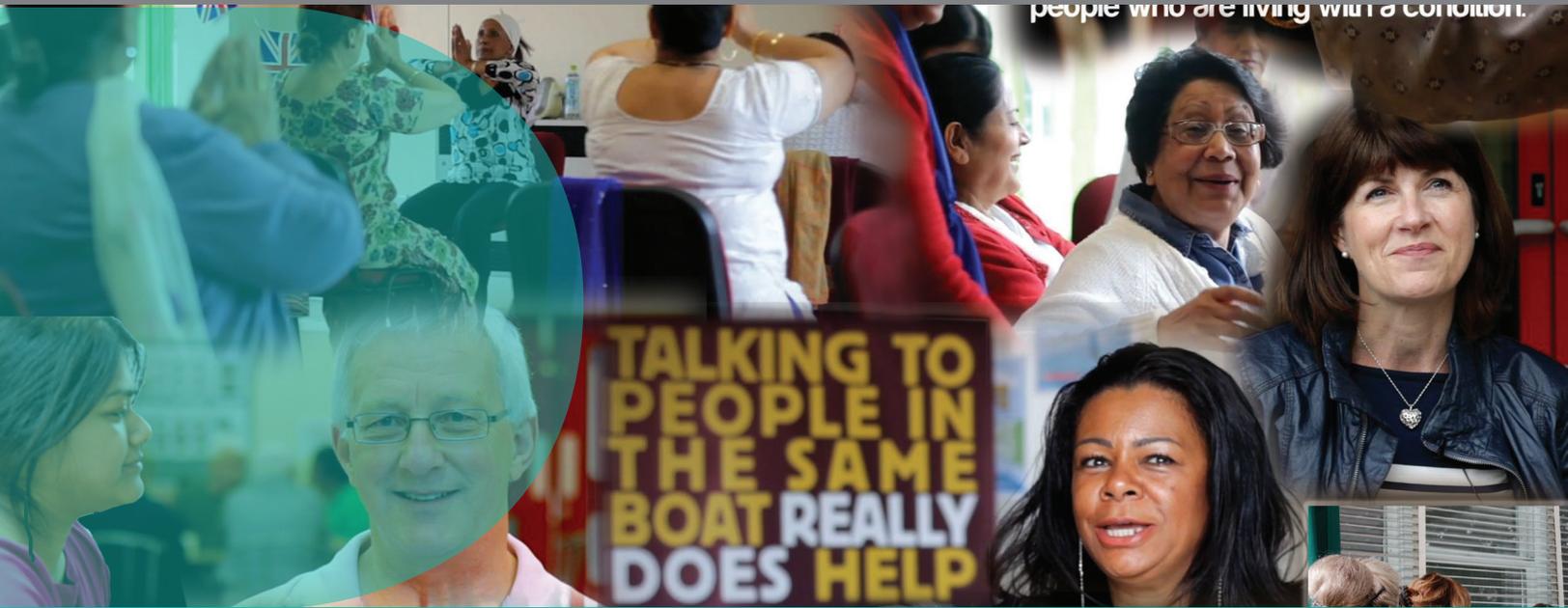
Recognising Self Help Nottingham and Nottinghamshire as a beacon for best practice, the Department of Health has asked us to work with other areas of the country to help them create the right environment for a supported self help group sector. Launching our national division – Self Help Connect UK – we can provide a range of support for commissioners and practitioners...

Commissioners

Innovating locally in Nottinghamshire, we have utilised our 30 years experience to develop services aimed at helping you to identify ways in which self help groups can be supported and promoted.

We can help you:

- create robust, high quality and sustainable information about self help groups
- enable groups to access support which will help the creation of new self help groups and aid the development of established groups
- promote the value of self help groups to the public and health and social care practitioners

Practitioners

Self Help Connect UK's website has lots of tips and advice for practioners working with groups. pack. Go to: **www.selfhelp.org.uk/ practitioners.**

More information at:
www.selfhelp.org.uk or call
David on 0115 911 1679

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Putting self help into practice – an introduction

At Self Help Nottingham and Nottinghamshire, we passionately believe in the power of self help to improve health and social well-being outcomes for people, and have been at the forefront of developing self help group support for more than 30 years.

Evidence that supports our understanding of how self help groups develop is vital, as it demonstrates that the range of services we can offer to practitioners working with groups are appropriate.

At Self Help Nottingham and Nottinghamshire we already had a lot of experience supporting practitioners who were working with groups, and it was this that led us to look for an opportunity to explore the needs of both groups and practitioners more closely in order to determine how best to build relationships between the two.

Our successful bid to the Big Lottery Fund Research Fund enabled us to do just that, and brought us together with some of the leading researchers in the field of self help groups to undertake the ESTEEM research project.

Over the course of the last three years, researchers from Nottingham University and Anglia Ruskin University have been working with self help group members and practitioners to glean information about what works, what doesn't, and what constitutes a successful partnership between groups and practitioners.

On behalf of the ESTEEM team I'd like to thank the self help groups who gave up their time to take part in this study, and the practitioners who offered their opinions and experiences.

And from a personal perspective, I'm pleased to see that this research backs up our belief that closer working relationships between groups and practitioners will deliver better outcomes for all parties. And I'm delighted that the study has been given a practical application in this guide and online resources.

Sarah Collis

Sarah Collis
Director, Self Help Nottingham and Nottinghamshire

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What is ESTEEM?

The three-year ESTEEM (Effective Support for Self Help/Mutual aid groups) research began in May 2010. Funded by the Big Lottery, the project is a partnership between Self Help Nottingham and Nottinghamshire, Anglia Ruskin University and the University of Nottingham.

The aim of the study, which was carried out by researchers at Nottingham University and Anglia Ruskin University, was to look at ways practitioners can best support local self help groups.

The research was a tale of two counties – Essex and Nottinghamshire – and examined the relationships between self help groups and health and social care practitioners in these two localities.

Although, throughout the research groups referred to themselves in different ways - support group, mutual aid group etc - for the purpose of this guide, we refer to self help groups.

We hope the findings of the research will help improve the quality of advice and support being given to self help groups by practitioners.

What are self help groups?

People often find it useful to talk to others who face the same issues or share the same experiences that they do. Whether that's dealing with a long-term medical condition or facing a life-changing experience like bereavement, self help groups are people who come together to offer and receive support. They usually centre round a community of interest (for example diabetes or bereavement) and can cover a variety of issues including:

- long-term medical conditions
- recovery from substance misuse
- difficult life situations
- mental health issues
- disabilities

People go to self help support groups for many different reasons. Some simply want information and will then move on, while others may want to make sense of what is happening to them by sharing their experiences with those who have been through something similar.

The most important thing, however, is that the support is there for people when they need it, whatever form it may take. And that is what self help groups provide.

The way a group describes itself, either by choice or by chance, is not necessarily a reliable indicator of the current level of self help activity or the degree to which practitioners are involved in the running of the group. Some independent and autonomous groups embrace the term 'self help', whilst others use 'support group' or 'peer support group'.

Conversely there are professionally-led groups which describe themselves as self help groups. Added to this, a group may change over time and may move between models, whilst retaining their original name.

Benefits for group participants

Participants recount lots of great benefits from getting involved with self help groups, including:

- Meeting, sharing and talking with others who have a similar condition or shared experience
- An end to isolation, leading to improved mood, health and well-being
- Accessing relevant information and advice
- Exploring new ideas and coping strategies

- Feeling empowered and better able to manage their condition
- A boost to their self esteem and confidence so they feel less isolated and anxious
- The opportunity to develop new skills

Why work with self help groups?

Figures recently cited by Health Minister Jeremy Hunt revealed that one in four of the population has a long-term condition, many of them older people. With this in mind, there's no doubt that we are going to have to think creatively about the solution.

Improved patient and public representation and support is at the heart of the National Health Service's drive to build service around the needs of the individual patient. Self help groups and mutual aid networks are growing in number and are likely to become increasingly significant in the rapidly changing health agenda, which emphasises partnerships and actively values the experience of users and carers.

Benefits of working with groups

Self help groups can complement the care offered by practitioners and ultimately support you in your role.

Working with a self help group can benefit you by:
- supporting the health and well-being of people in your area
- helping improve the health and well-being of your patients/clients
- helping you communicate key health and well-being messages to group members and the wider communities
- helping you clarify information about health care, political changes, new developments and support
- providing access to people who can help with service design
- supporting your professional development

The way a group describes itself, either by choice or by chance, is not necessarily a reliable indicator of the current level of self help activity or the degree to which practitioners are involved in its running. Some independent and autonomous groups embrace the term 'self help', whilst others use 'support group' or 'peer support group'. Conversely there are professionally-led groups which describe themselves as self help groups. Also, a group may change over time and may move between models, whilst retaining their original name.

The ESTEEM study

In the first stage of the study, we used qualitative methods to achieve a thorough understanding of self help groups (SHGs) in the two counties...

A total sample of twenty-one SHGs (ten from Nottingham and eleven from Essex) were selected in order to provide a broad range of groups at different stages of development and with various structures who were addressing a variety of health and social issues.

Individual interviews were conducted with group coordinators and group discussion interviews were held with ten of the groups in each area.

In addition, ten interviews were held with self help experts from national charities affiliated with local groups, voluntary sector agencies working with community groups and self help groups, a service user networkfor people from Black, Asian and minority ethnic communities and community development agencies.

The full first phase of the study - ESTEEM Project Stage One Interim Report October 2011 - can be viewd at: www.selfhelp.org/esteem.

In the second stage, a participative approach was used to identify the training and support needs of groups and to identify best practices for practitioners in supporting these groups.

Six groups, who participated in Stage One (three from each location) were asked to recommend up to three practitioners for inclusion in the study who had supported the group during their development.
The second phase of the study - ESTEEM Project Stage Two Report March 2013 can also be found at **www.selfhelp.org.uk/esteem.**

Key findings

The ESTEEM study highlights the importance of building trust between practitioners and groups identifying it as crucial to developing good working relations.

There was broad agreement that for practitioners to work effectively with groups they need to recognise and value the benefits associated with peers supporting one another.

The research revealed a number of key findings:

Groups and the benefits

- Groups worked with practitioners from numerous organisations, including health and welfare services, schools and voluntary sector agencies. Relationships were frequently very positive, with assistance coming from local support agencies. This assistance included informal support and advice, help with the costs of printing and premises, and training in areas such as accounting and funding applications.
- Group members saw themselves as 'community,' 'peer,' 'support' and even 'friendship' groups. They believed that sharing their own experiences was the source of the group's wisdom and that being peer-led was essential.
- Groups varied widely in their organisational structures, relying on a relaxed atmosphere and democratic decision-making. All groups had somebody who fulfilled a leadership or coordinator role.
- Participants believed that mutual support could counter social isolation, increase self confidence and help people to cope with health and social conditions. They shared information between themselves and also saw the group as a source of information within a community.

Practitioner relationships

- Practitioners believed that the activities of groups could enhance the beneficial effects of health and social care services and potentially reduce service costs.
- Some practitioners had an interest in supporting groups in order to encourage local participation, community empowerment, and build social capital. Most spoke of a mutual benefit from their involvement with groups.
- Practitioners provided support to groups in four areas: organisational development (infrastructure and resources); nurturing members and process (leadership, capacity, participation, group dynamics); enhancing and sharing expertise (increasing knowledge and understanding); increasing connections, credibility and influence (promoting profile, voice and understanding within the NHS and local community).
- Practitioners recognised a number of challenges in working with groups, with particular concerns over boundaries and limits to professional responsibility, such as confidentiality, sharing information, recruitment to groups.
- Practitioners understood that each group is unique, dependent upon the character of the leader and the reliability, capability and wishes of the membership. They also felt that this presents a challenge in achieving a balance between supporting the group leaders and helping the membership run it for themselves.
- Practitioners recognised the importance of groups being peer-led. However, their understanding of a group being 'run by and for its members' was nuanced, and they were usually prepared to support groups displaying a range of leadership models.
- Five broad practitioner roles were identified from study. These roles are not mutually exclusive and recognising which role is appropriate for the group at that particular time and which was achievable for the practitioner was key.

Recognising an appropriate role for the practitioner was key to avoiding tension and achieving successful support. The roles were identified as:

- resource-builder
- capacity-builder
- facilitator
- bridge-builder
- co-educator

Important to note!

The way a group describes itself is not necessarily a reliable indicator of the current level of self help activity or the degree to which practitioners are involved in the running of the group.

Some independent and autonomous groups embrace the term 'self help', whilst others use 'support group' or 'peer support group'. Conversely there are professionally-led groups which describe themselves as self help groups.

Added to this, a group may change over time and may move between models, whilst retaining their original name.

What role can you play?

The ESTEEM research identified five typical roles that practitioners take on when successfully working with a self help group. There roles are not mutually exclusive and you may find yourself getting involved in different aspects of support which span all five roles or just a specific activity within one...

The resource builder

A resource builder provides all kinds of practical help. This role is particularly important during the start up of a group. A practitioner who fulfils this role will typically do all or one of the following:

- make relevant resources available to groups
- help members identify, secure and account for suitable funding
- help members access other services to support group growth and development

> "I simply mentioned that a large well known hotel chain had once offered a group a free meeting room. That was all the ammunition she needed. Next thing I knew she had secured a free meeting room for her new group at a very swanky venue."
> **The resource builder**
> **Caroline Bell, training manager, Self Help Nottingham and Nottinghamshire**

The capacity builder

A capacity builder will tend to work with a group or key members over an extended period covering areas like:

- helping to develop a group's confidence through group activities
- providing the necessary tools to aid the running of the group (like finding a suitable venue)
- delivering formal training or taking a coaching role where group members were involved
- acting as critical friend and encouraging group members to reflect on ways of doing things

- signposting to other organisations which can help the group if required
- taking a lead in a group when required and ensuring they are there to help develop a group
- acting as mediator in response to deteriorating group member relationships, in some cases helping to close the group

The facilitator

A facilitator will support groups through periods of difficulty, struggle or conflict, even helping them come to a close if necessary. This is a more hands-on role, offering types of support that may be needed throughout the life cycle of a group, such as:

- helping building sustainability at the outset of the group
- providing support to identify opportunities for growth

The bridge builder

The bridge builder puts people, groups and agencies in touch with each other. This is especially useful in the NHS, where groups sometimes struggle to be heard and respected. A bridge builder will typically:

- connect groups to the practitioner community
- promote groups to patients/individuals with similar issues
- signpost to other support and community organisations

"I think it's how you package it for them, so you say 'we're doing a training course on confidence building for everybody, come along, it could be a bit of fun'. Just drip feed people confidence and acknowledgements that it's a good thing"
The capacity builder
Helene Torr
Parent Partnership

'I encouraged them to do a teaching evening so we have one evening a year where a couple of consultants come along. They like it because they get the chance to ask questions of the consultants, it's a different dynamic, rather than them sitting across the table from the consultant and being told something about themselves.'
Bridge Builder
Nikki Scarlioli,
Macmillan Specialist Nurse,
Prostate Cancer

'Typically what we do is talk to the members, the general membership about what it is that their committee does for them, why it's important to have a committee, do they really want the group to exist because actually more often than not if there's no committee the group will fold - We see if we can help them with volunteers that way.'
The facilitator
Margo Barsi, area development manager
Arthritis Care Central England

'Quite a lot of us from the hospital will go along just to keep ourselves up to date with it. And I find myself learning and when I learn I feel excited and/or exposed.'

Co-educator, Clinical manager for a nutrition and dietetic services from Mid Essex Hospital Trust
Pauline Bird

- promote targeted health messages to groups to keep them up-to-date
- encourage participation in health and social care service delivery

The co-educator

The co-educator will support the peer-to-peer learning activities that underpin successful self help. They typically cover a range of activities including:

- sharing professional knowledge and expertise via presentations, forums, informal Q&As at group sessions
- promoting equality and diversity

Of all the roles, the co-educator was identified as a key position in terms of benefitting from individual learning and continuous professional development, learning from other groups and other practitioners.

More guidance about how practitioners can work with self help groups is available at: www.selfhelp.org/practitioners.

Top tips from the ESTEEM practitioners:

- be clear about your role and its limits
- help raise awareness to boost the group's local profile and credibility
- value different kinds of expertise and support
- be friendly, approachable, non-judgemental and flexible
- be positive: assess the risks and take a 'leap of faith'

Building a successful partnership with a group

There are a number of key factors to consider when you're trying to build a relationship with a group...

Confidentiality is important

Groups are more likely to flourish when members feel sure that what they say is not going to be repeated outside the meeting. Each group will decide exactly what is right for them, but there should always be some agreement on confidentiality.

Group members take the decisions

Decisions on how the group runs and what it does are best taken by the group as a whole. While there may be a few people who are more active (or vocal) than others, everyone should have a chance to have their say.

Clear aims strengthen the group

Always understand what a groups aims are. And if they don't appear to have any, encourage them to try and develop some. Groups with clear aims are much more likely to succeed.

Help the group to decide who can be a member

It's fine for the group to set limits and boundaries as to who can be a member. It's important to say whether relatives or practitioners are welcome.

Keep it simple at first

Simple, manageable activities work best at first, as the group is likely to see results within a reasonably short time. They can always add more complex activities as the group develops and is ready for change. Encourage the group to work within the limits of their members' energy and time.

Encourage the group to give and receive help

Groups work well where there is no clear division between givers and receivers of help. Encourage the group to share the jobs around.

A positive side to the group

Groups often involve sharing difficulties and sadness. Encourage the group to give some thought to whether they can create opportunities for people to talk about the good things in their lives, to share coping strategies and activities which enable people to feel more positive.

Encourage them to celebrate their achievements

Suggest the group stops every now and then to look at what they have achieved as a group. Encourage people to reflect on how they have changed and what the group has done for them.

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Acknowledgements

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The overall management of the project is led by:
Self Help Nottingham and Nottinghamshire
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Project Advisory Group
A project advisory group, comprising the project management team and additional representation from the Department of Health, health and social care commissioning, practitioners, academics and self help groups, met every four months to monitor the progress of the study and advise on issues arising.

www.selfhelp.org.uk/esteem