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

Final Report Executive Summary

May 2013

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Acknowledgements

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Project management team

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 team and additional representation from the Department of Health, health and social care commissioning, practitioners, academics and self help / mutual aid groups, met every four months to monitor the progress of the study and advise on issues arising.

1. Introduction

Self help groups (SHGs) are run voluntarily by and for members living with a shared health condition or social issue. They provide a space for mutual support and learning based on members' experiences and knowledge. This is different to the support delivered by health and social care practitioners who may not appreciate the distinctive nature of SHGs or the benefits felt by members.

The ESTEEM project was designed to bridge this gap in understanding. Its aims were to: develop a typology of SHGs; identify SHGs' training and support needs at different stages of their development; and produce and disseminate good practice resources in order to facilitate effective collaboration between SHGs and health and social care practitioners.

The project was a partnership between Self Help Nottingham, Anglia Ruskin University and the University of Nottingham. It was funded by the Big Lottery.

2. Methods

The study took place in Nottingham and Essex. It began in May 2010 and was conducted using participatory, qualitative methods in two main phases over a period of 36 months. A third phase of dissemination began in January 2013 and will continue until December 2013.

In the first stage of the study, qualitative methods were used to gain a thorough understanding of SHGs in the study locations. A sample of twenty-one SHGs, ten in Nottingham and eleven in Essex, was selected in order to provide a range of groups at different stages of development, with various structures, and addressing a variety of health and social issues. Individual interviews were conducted with group coordinators and group discussion interviews were held with the SHGs in each area. In addition, ten interviews were held with self help experts from national charities with affiliated local groups, voluntary sector agencies working with community groups and SHGs, a service user network for people from Black, Asian and minority ethnic communities and community development agencies. The first phase of the study is described in further detail in the ESTEEM Project Stage One Interim Report October 2011

In the second stage of the study, a participatory approach was used to identify the training and support needs of self-help groups and to identify best practices for practitioners in supporting these groups. Six SHGs who participated in phase one (three from each study 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 was reported in detail in the ESTEEM Project Stage Two Report March 2013.

3. Findings

3.1 Self Help Groups

Overview

The twenty SHGs included in the study addressed an array of health conditions and life situations. They comprised ten physical health groups for long-term conditions, five mental health groups, and five social issue groups for parents, ethnic minority communities and gay men. Five groups were gender specific. Most groups not only offered support and information, but also thought that they provided a pathway to social participation for members, and placed a high value on social contacts and activities beyond regular meetings. Groups ranged in size from two or three to groups with more than thirty members who frequently attended meetings. The groups met regularly, with a range from weekly to quarterly, in settings such as cafes, hospitals, voluntary sector agency offices and community centres.

Ethos, purpose and activities

Groups identified themselves in terms far broader than 'self help' expressing their fluid multi-faceted nature – they saw themselves as 'community,' 'peer,' 'support' and even 'friendship' groups. The diversity and idiosyncrasy in the nature of the twenty-one groups we studied was such that no typology of groups beyond their reason for meeting proved possible.

Members believed that their own experiences were the source of the group's wisdom. Despite the emphasis on members' knowledge, many groups placed a high value on input from practitioners, such as specialist nurses, who were frequently invited to speak at meetings.

Mutual support was perceived by the majority of groups to be the unique, defining feature of SHGs. It was the process through which many of the benefits associated with group membership were realised. Sharing information was a primary purpose for nearly all groups. Members offered their collective experiences as a resource for getting the best out of services and making the most of life. Members also perceived their role as spreading information beyond the group, for example by taking part in awareness sessions to educate people about their condition and reduce any stigma that attached to it. A small number of SHGs were developing to be able to deliver services, such as children's activities and parents' drop-ins, sometimes run in partnership with public agencies. They did not see this as changing their ethos of mutuality and informality.

Groups saw themselves as links within community networks, working with schools, pharmacies, employers, health and welfare agencies, and other self help and voluntary groups. Many SHG members also attended other community meetings and consultation forums that aimed to influence statutory services.

Impact

The potential impact of membership of a SHG cannot be overstated. Whilst some members primarily saw the group as a means of accessing information or participating on a social level, for others being part of the group had been a life changing experience. Members reported a sense of increased well-being, greater self confidence, reduced feelings of isolation, improved physical and mental health and a better ability to cope.

Group structure

The groups ranged from having no structure at all to being fully constituted as charities. The unstructured groups felt that a formal structure might undermine their egalitarian ethos and informality. Those with charitable status had generally taken this step for funding purposes and also because they felt it increased their credibility, however, they noted that the administrative responsibilities attached to acquiring charitable status could be onerous.

Most groups' structures were somewhere in between these two extremes entailing some form of management committee and a written constitution. There was concern that formalisation could 'put a barrier up' between members, but on the whole groups maintained a friendly, relaxed atmosphere and democratic decision making processes. All groups had someone, or a small core group of people, who, with differing levels of formality, fulfilled a leadership role. This role often required considerable time and commitment.

The extent of collective responsibility for undertaking group tasks varied widely. In some groups there were high levels of member input but, in others, group coordinators found their role burdensome due to members' reluctance or inability to assist with running the group.

Eight groups were affiliated to a national organisation. The quality of relationships with national organisations varied. They were most positive when the national body was available for support and trusted the group to act independently in response to their particular local needs. Groups felt aggrieved when their freedom to act was restricted or when they were treated as a fund raising 'money-box' for the parent organisation.

Funding

Most groups needed some funds to cover their running costs; these were generally obtained through member contributions. The biggest expense was for meeting premises, although a number of groups, particularly those in Nottingham, benefitted from reduced rents at a variety of venues. Revenue was also used for hosting events, publicity, days out, paying for speakers, transport and administrative costs. Although some groups stated that they had 'simple needs' and did not require much money, many were struggling due to a lack of funds.

There was a common fear that receipt of grant funding would either undermine groups' ethos and independence or subject them to an unwelcome degree of accountability. However, only three groups had not applied for some funding. The remainder had accessed revenue from a number of different bodies, including local councils, local community funding agencies, the Big Lottery and national charities. Funding application processes were generally seen as a 'big headache' for which most groups needed assistance.

External relationships

Groups worked with practitioners from many organisations, including health and welfare services, schools and voluntary sector agencies. Assistance came from agencies such as Self Help Nottingham, Nottinghamshire Community Foundation and, particularly in Essex, local Community and Volunteer Service offices.

3.2 Expert practitioners

Overview

In total, twenty-six practitioners with expertise in supporting self-help groups were interviewed across both phases of the study. Fourteen interviewees were based in the voluntary sector, six in the local authority and six in the NHS sectors.

Practitioners acknowledged that membership of a SHG could provide direct health benefits to individuals through improving knowledge, self-confidence, information about welfare, local services, facilities and opportunities, as well as overcoming social isolation. They also saw SHGs as a means of consolidating and enhancing the effects of health and social care services.

Practitioners identified a wider social contribution that SHGs can make in connecting local communities. They recognised that SHGs were able to act as channels of information about a wider range of topics than just self help and could have a direct impact on the community through re-engaging people, especially those within traditionally excluded populations.

They were optimistic about the future of SHGs although this was tempered by concern about the effects of the current economic climate and public spending cuts. It was believed that groups would have to find new ways of working and financing their activities.

Practitioners' motivations for involvement in SHGs

Practitioners' involvement in SHGs was motivated by a mix of professional and personal interests. On the whole, practitioners supported groups because they saw it as part of their job, at an individual or wider organisational level. They saw SHGs as a means of consolidating and enhancing the beneficial effects of health and social care services, and believed SHGs could save service costs. Some practitioners had an interest in encouraging local participation and community empowerment.

Most practitioners spoke of a mutual benefit from their involvement in groups. They valued the opportunity to meet people in a less formal capacity and to increase their awareness of issues of importance to people directly affected by a health or social condition.

In general, approaches to working with groups varied between **collaborative or responsive to specific needs,** but most practitioners recognised that groups should aim to be member-led. They felt that their level of involvement should, as far as possible, reflect the needs of the groups as perceived by the members themselves.

The span of practitioner support

The extent of the practitioners' involvement in SHGs varied widely. Voluntary and community sector practitioners saw their role to support all aspects of group development, while health and social care practitioners often had a more specific focus for their involvement such as information exchange. There were broadly four areas in which practitioners provided support: organisational development (infrastructure and resources); nurturing members and process (leadership, capacity, participation, 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).

Organisational Development: Practitioners provided assistance with practical issues such as printing leaflets, organising events, borrowing technical equipment, and supplying guides and advice booklets on community groups and other printed resources. However, for most groups their most pressing need was for practical help to find affordable and appropriate venues for their meetings. It was a concern for all practitioners to achieve the right balance between 'hands-on' support and avoiding dependency.

Most practitioners felt that groups needed particularly high levels of support during the starting up stage, and a more directive approach was sometimes needed. Groups were particularly appreciative of 'starter packs' and 'starter grants'.

Nurturing members and group processes: Many practitioners equated their support for the group with support for the group leader. Practitioners offered mentoring to group leaders or directed them to leadership training events and 'key-members' days offered by national or local charities. Practitioners agreed that a group leader was best supported by an actively involved membership, and, in some cases, practitioners intervened to promote active member involvement.

Practitioners also directed members to training events that would support self-reliance, such as listening, assertiveness, confidentiality, book-keeping, marketing, computer and English language skills. Peer to peer learning offered by some voluntary sector and national charity organisations was highly valued by group members and practitioners.

Practitioners also helped to develop a group's capacity by adopting an informal position as a 'critical friend'. This allowed them to offer constructive but not prescriptive suggestions and raise challenging issues. Practitioners were also in a position to highlight the work of groups within their local communities, and increase a group's recognition.

Information and exchange of learning: A common way of achieving this was for practitioners to use their contacts to access and arrange for speakers at the groups' request. Practitioners also gave advice, provided information in more informal ways to individuals at group meetings or, occasionally, outside meetings.

Health and social care practitioners emphasised the reciprocal nature of the learning, and stressed that they learnt about group members and the problems they experienced and the strategies they employed to deal with them, which, in turn, could inform service development.

Practitioners thought that they had an important linking or signposting role, enabling groups to access and build useful relationships with the appropriate people in the local community. Practitioners recognised that many groups, although not all, wanted to be involved in public and patient involvement processes and to influence health and social care services.

Complexities and tensions for practitioners

Practitioners discussed the challenges facing them in working with SHGs in three broad areas: their working relationships with self-help groups, the changing support needs of groups over time, and facilitation to achieve inclusive and participatory practice.

Practitioners highlighted that their ways of working often diverged from those of SHGs, noting the informal meeting structure of groups, the timing of meetings organised around members'

circumstances or infrequent meetings leading to slow response when practitioners are under pressure to meet targets.

Practitioners described a variety of challenges to their expertise when working with SHGs, including from colleagues who were antagonistic to self help. Practitioners also identified that their work with self-help groups could raise concern over boundaries and limits to professional responsibility, with ambiguities over confidentiality and sharing information. Practitioners believed that the most effective way of managing and maintaining boundaries and avoiding this type of confusion was to be clear from the outset about what they could offer to groups and the limits to their relationship

A perception amongst group members that practitioners did not actively support recruitment of new group members was a source of some frustrations. The ability of a group to attract new members was often seen to be dependant upon practitioners directing new members to the group. Practitioners were usually willing to help groups with producing literature but they were aware that such information would have limited effect on groups' membership and needed to engage in broader discussions about attracting new members. The nature of SHGs meant that a group facing closure or winding up is not unusual. There was little clarity about whether practitioners should help group members bring about closure or strive to keep groups going.

A very small number of practitioners argued that professionally facilitated groups could also be SHGs, and there were differences of opinion on whether some groups required facilitation because of the vulnerabilities of members. However, all practitioners emphasised the importance of promoting group autonomy and providing clarity about the limits of their role to avoid dependency.

Practitioners expressed different views about encouraging the participation of people from different ethnic backgrounds in SHGs. A number of practitioners believed that, where appropriate, they should actively encourage groups to engage more widely and reach out to new populations, although it was recognised that groups were autonomous.

A few practitioners highlighted the problems that could arise when SHGs were invited to take part in public consultations. Several practitioners saw themselves as having an important function in speaking on behalf of group members, especially in more formal meetings. However, there were concerns that speaking on behalf of groups could be seen as patronising or disempowering.

Working with self help groups successfully

The importance of trust between practitioners and SHGs was identified 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 following outline advice to practitioners working with SHGs was formulated: *Be clear about your role and its limits*; *Help groups get a 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'*

4. Discussion

Overall the study has highlighted the complexities and nuances in the relationships that practitioners can have with SHGs. One established criteria for SHGs is that they are member–led, this definition tends to imply that practitioners are 'invited guests' to groups, however, a more complex picture emerged with a range of roles and activities that practitioners contribute to group development. This inevitably raises questions about ownership and control of groups.

4.1 Practitioner involvement groups: issues of ownership and control

The autonomy ascribed to SHGs was not straight-forward. We found a spectrum of autonomy across different kinds of groups but also within the same groups at different times in their evolution. The key questions for practitioners in addressing the autonomy of SHGs are: Who makes the decisions? Who runs the meetings and organises the activities? Who feels a sense of ownership?

New groups often needed more practitioner support than established groups but there was a fundamental difference between those groups instigated by practitioners (often health and social care professionals) and those instigated by people with the condition or social issue around which the group was focused. In keeping with existing literature in the field, groups founded by peers develop a strong sense of mutual ownership, whereas member ownership may be unclear or undeveloped when it has been professionally instigated. However, this simple distinction falls apart where practitioners set up groups with a clear remit for the group to be member led, or provide transitional facilitation in order to develop from a professionally led group to become peer led.

4.2 Practitioner roles

Judy Wilson (1995) argued practitioners working with SHGs must be clear about the role they are taking within a group and recognise how this role might need to change over time. Five broad practitioner roles were identified from the ESTEEM data. These roles were partly linked to the practitioner's remit, but contextual factors, such as the needs and developmental stage of the group, also played an important part. The identified roles are not mutually exclusive; and recognising which role was appropriate for the group at a particular time and achievable for the practitioner was key. These five broad roles were 'resource-builder', 'capacity-builder', 'facilitator', 'bridge-builder' and 'co-educator'.

Resource-builder: offering practical help of different kinds, it usually involved making resources that were accessible to practitioners readily available to groups. This role, particularly for practitioners in the voluntary sector, may also involve helping to identify, secure and account for suitable funding.

Capacity-builder: working with a group or key members over an extended period usually helping to develop a group's confidence and providing them with the necessary tools to aid the running of the group. This role may involve identifying training opportunities or taking a coaching role where group members were actively involved and leading the process. Another approach was to become a critical friend to the groups, where practitioners encouraged group members to reflect on alternative ways of doing things.

Facilitator: sustaining a SHG through periods of difficulty, struggle or conflict, and helping them come to a close if necessary. Differing types of support may be needed throughout the life cycle of a group, from building sustainability at the outset of the group, coming to terms with the loss of key members through to dealing with the need for a group's closure. Sometimes facilitators acted as a mediator in response to deteriorating group member relationships.

Bridge-builder: putting people, groups and agencies in touch with each other, it was especially useful in the NHS where groups sometimes struggled to be heard and respected. Groups that were starting out or floundering in some way benefited when a practitioner was able to link them to relevant networks, organisations, individuals and other self-help groups; it also strengthened their community status. Through the development of these links and networks, groups were in a more favourable position to promote their voice. Sometimes bridge-building involved helping people from different sectors to understand each other.

Co-educator: supporting the peer to peer learning activities that underpin successful self help, demonstrating that they had as much to learn from the group members as to give. Some spoke of 'co-production' and that mutual learning provided a solid foundation for this approach to service development.

4.3 Issues that impact on the role and involvement of practitioners with SHGs.

Self help groups are diverse and idiosyncratic; there are many contextual factors that make each SHG unique, including the character of the leader and the reliability, capability and wishes of the membership. This presents a challenge to practitioners who wish to work with SHGs, and there is a balance to be maintained between support for group leaders and helping the membership to run it for themselves. A prescriptive approach to leadership or members' roles may risk undermining a delicate balance that is peculiar to each group's circumstances. Our findings show that groups can run very successfully with a strong individual leader and very little input from the broader membership.

Practitioners are aware of the importance of SHGs being peer led. However, their understanding of a group being 'run by and for its members' had many nuances. Whilst there were reservations expressed by a very small minority of practitioners about the potential for some types of groups to be fully member led – in the main these reservations were about mental health groups and involved issues about undue stress on co-ordinators or safeguarding issues – concerns that have not been reported elsewhere in the user-led mental health literature.

A number of practitioners had been responsible for introducing volunteers into SHGs, for example to assist with accounting or to take on committee roles, because they believed that otherwise a group would not be viable. It suggests that practitioners' views on volunteers indicate a move away from traditional ideas of self help towards more flexible, hybrid models that incorporate a wider range of participants.

Conclusion

The broad and diverse range of practitioners that contributed to this study highlight the varied ways that practitioners are working with SHGs. These collaborative relationships were partly linked to the

practitioner's job role, but contextual factors, such as the needs of the group, also played an important role. The practitioner and group member accounts illustrate a range of benefits arising through collaborative partnership working, such as the facilitation of mutual learning and networking opportunities. Similarly distinct areas of tensions and challenges were raised, for example around facilitation that had the potential to foster misunderstanding and frustration. Recognising the role practitioners can adopt, which is suitable for the group and attainable for the practitioner was often key to avoiding and managing these tensions.

Outputs from the ESTEEM project

Reports

ESTEEM (2011). Stage One Interim Report. Self Help Nottingham, Nottingham.

ESTEEM (2013). Stage Two Report. Self Help Nottingham, Nottingham.

List of published papers

Seebohm, P., Chaudhary, S., Boyce, M., Elkan, R., Avis, M. & Munn-Giddings, C. (2013) The contribution of self-help/mutual aid groups to mental well-being. *Health & Social Care in the Community*. DOI: 10.1111/hsc.12021.

Visram, N., Roberts, A., Seebohm, P., Boyce, M. & Chaudhary. (2012). The role of self-help groups in promoting well-being: experiences from a cancer group. *Mental Health & Social Inclusion* 16(3), 139-146.

Other resources

ESTEEM (2012). Typology of Self Help Groups Paper. Self Help Nottingham, Nottingham.

Putting self help into practice: A guide to working with self help groups for professionals. (2013) Self Help Notttingam, Nottingham.