

peerfest 14

‘Starting up and keeping going’

A workshop with Krys Farrell, Catherine Swain and Shirley Lindo

Krys Farrell opened by sharing her experiences of self-help and the impact this had on her mental health and the road she has taken to setting up and facilitating self-help groups over the last 30 years.

Catherine Swain and Shirley Lindo shared their experiences of setting up the Medex group. This group came out of a desire to reduce medication and recognition that the support of a peer would be valuable during the process of reducing medication. The support took on the form of group meetings. The benefits of advocating for peers in meetings with for example a psychiatrist was also explored.

Krys clarified that self-help groups start because people have identified something that they want *for themselves*. This is different from a service provider deciding to start a group *for other people*. *The key is, who has identified the need? and who has ultimate responsibility?*

Starting up



(Layby reflections Wales 2013)

Looking at the existing landscape. A long process of evolution has led to this. It's useful to remember the long history of self-help. This includes 'consciousness raising' and groups forming as a result of barriers to other forms of support (particularly relevant for people from communities that experience discrimination or when there is an absence of culturally appropriate support).

Starting up a self help group is a process. Finding an image or music that represents your idea can be a useful starting point.

Workshop participants shared their ideas and what they were looking to do. Examples included starting a group for people living with anxiety, a group for people experiencing paranoia, a group for people from LGB&T communities with mental health problems who may experience stigma when accessing services.

Things to consider when starting up:

- Who is the group for, what do you want to do and why?
- What will the size of the group be?
- Will it be an open or closed group? Will this change with time?
- Will there be a time limit to the group – when will it end?
- Will you use a closed/private group on Facebook or yahoo to keep in contact?
- What 'agreement' or 'ground rules' will group members come up with and commit to?
- Where will you meet, are there any access issues?
- What support do you have personally or if wanted professional/resources...?

Keeping going - beware of sharks!

(Valencia –Oceanografic 2014 by Azura)



Formalisation and funding

Some processes of formalisation, such as constituting a group and applying for funding, can compromise the way in which a group works. For example, becoming accountable to an external funder could mean having to formulate and measure the impact of the group in a way that a funder comprehends.

Participants shared useful suggestions:

- Community fundraising, such as holding a raffle, could be used to raise small amounts of money
- Group members could contribute small amounts to cover tea, printing, room hire etc.

- Local authorities may have a community fund. If there are limited costs and the group doesn't have a bank account, invoices (e.g. for room hire) could go through the local council
- Financial records should be kept - doesn't have to be a complex system

Risks and responsibility

The importance of trying to remain autonomous as a self help group was also explored. There were questions and discussions around risk and accountability. Workshops leaders returned to the key tenet of group members taking responsibility for themselves and the importance of individual decision-making and choice.

'Leaders' and the core group

Another issue relating to 'keeping going' concerns leadership. It is natural that leaders emerge from within groups. However, the group will need to consider how those people can deputise and where and how 'leaders' receive support. It's also natural for a group to have a 'core group' of regular attendees. Beware of spending time noting the absence of other members, rather than sharing support with those that are present!

One solution to these issues is to engage the help of a 'floating self-help worker'. This person, external to the group, could help with a different perspective on group dynamics or to provide support to the core members of the group.

Ending

Groups come to an end, and this doesn't have to be a bad thing. Groups often work for a while but may conclude if the reason for meeting has been achieved or if core members move on.

Ownership and professionalisation

Workshop leaders shared reflections on the risks facing self-help. Professionalization and profit making could take self-help away from its roots. Krys advised caution around the expectation that people need a qualification to speak to each other. Krys also questioned the validity of the belief that one needs formal qualifications to talk to and engage with fellow peers. In the same way that we remain aware of the history of self-help, we need to be aware of its future and the different agendas that are at play within the User Movement and other mental health services/organisations.

Participants reasons for being at the workshop

- ❖ Learn from experience. Find out if there is anything of which may be of interest for my son to give an improved quality of life
- ❖ To make it happen
- ❖ I am in the process of setting up a self-help group
- ❖ Meet local unmet need in Portsmouth
- ❖ Interested in the difference between 'paid' and not 'paid' peer support. How do the 'not paid' not get exploited
- ❖ Interested in finding out more about how others start things & keep them going so I can share with others in similar position
- ❖ Set up peer led activities to help improve health and wellbeing
- ❖ Be inspired by the experiences of others
- ❖ Companionship and support campaigning sharing information/advocacy

- ❖ Interest
- ❖ Hear about peoples experience of peer support / what makes good peer support / how do you do it well
- ❖ To make a difference / To learn how to start up a self-help group / To help people learn that recovery is possible / To help people with mental health issues feel less isolated
- ❖ Involve people with experience of using services in their design
- ❖ Sustain an existing group. Funding –sources
- ❖ Support & Advice maintaining self-support group
- ❖ To learn how to help people who want to set up their own self-help groups
- ❖ Want to start up support for modified people / 1. Learn from others 2. Find out ideas
- ❖ Keeping momentum going with a self-help group
- ❖ Hear other peoples experiences and share mine
- ❖ Start a group for anxiety sufferers / Share my experience to benefit others
- ❖ For sharing, learning and mutual encouragement and inspiration. I am in the process of helping set up a group-run peer support group. We have ideas about why we are setting it up, but we don't all have the same objectives. I hope we largely share the same core values and ethos. I came here to hear about how others approach setting up groups (we have our third meeting Monday!) personally I want to help facilitate setting this up for others – not for myself –so I don't fell hung up on approaches. (It comes directly from my experiences – struggling coming out of depression. Not wanting anyone to be as isolated as I was).
- ❖ Find out about what's going on around me / find out how to keep going / find out how to grow into the wider community (how to integrate) / interested in having a large umbrella network (database).
- ❖ Starting up an l.g.b.t group for people living with mental health
- ❖ Ideas on how to start up group to support adults with experience of bullying. Charities lend to just support children. Long term effects don't get addressed. Also to deal with bullying during adulthood and fight stigma.
- ❖ Growing & sustaining beyond the initial group.
- ❖ Insight and ideas for crisis groups - what's been helpful advice to others
- ❖ Interested in peer support
- ❖ Support for new women's group & help to start up further groups