



Journal of Integrated Care

Strategies for Living

Alison Faulkner Vicky Nicholls

Article information:

To cite this document:

Alison Faulkner Vicky Nicholls, (2001), "Strategies for Living", Journal of Integrated Care, Vol. 9 Iss 1 pp. 32 - 36

Permanent link to this document:

<http://dx.doi.org/10.1108/14769018200100006>

Downloaded on: 29 February 2016, At: 01:22 (PT)

References: this document contains references to 0 other documents.

To copy this document: permissions@emeraldinsight.com

The fulltext of this document has been downloaded 107 times since 2006*



Access to this document was granted through an Emerald subscription provided by emerald-srm:145665 []

For Authors

If you would like to write for this, or any other Emerald publication, then please use our Emerald for Authors service information about how to choose which publication to write for and submission guidelines are available for all. Please visit www.emeraldinsight.com/authors for more information.

About Emerald www.emeraldinsight.com

Emerald is a global publisher linking research and practice to the benefit of society. The company manages a portfolio of more than 290 journals and over 2,350 books and book series volumes, as well as providing an extensive range of online products and additional customer resources and services.

Emerald is both COUNTER 4 and TRANSFER compliant. The organization is a partner of the Committee on Publication Ethics (COPE) and also works with Portico and the LOCKSS initiative for digital archive preservation.

*Related content and download information correct at time of download.

Alison Faulkner

PROGRAMME MANAGER

and

Vicky Nicholls

RESEARCH AND

TRAINING CO-ORDINATOR

STRATEGIES FOR LIVING PROJECT,
MENTAL HEALTH FOUNDATION

ABSTRACT

This article provides a discussion of the value of user-led research in mental health, with particular reference to the *Strategies for Living* project at the Mental Health Foundation.

Strategies for Living

If you asked for the words that spring to mind on the subject of research, likely responses would include 'professional', 'academic' and even 'worthy'. Expertise is traditionally seen as resting with academics, researchers and service providers, while the position of people who actually use mental health services is usually that of being researched – being the material rather than the instigators.

The Mental Health Foundation's *Strategies for Living* programme challenges this assumption. The basis of the whole programme is the recognition of the individual as the primary expert on their own mental health – a view that is gaining recognition across the sector. The Mental Health Foundation is now developing a unique UK-wide programme of user-led research that will build on the experiences of a smaller user-led research programme which has run over the past two years.

What is user-led research?

By user-led research we mean just that; developing the topics for research, deciding on the approach and conducting the research are all done by mental health service users and survivors. Researchers will be supported by people with experience of mental health problems.

We know from the Mental Health Foundation's current experience that this does colour the research itself. Whereas more typical scientific research focuses very largely on individual services and treatments, user-led research starts from the basis that everybody's personal experiences and personal expertise are valid, that there are, in many cases, no single right answers. What is important is enabling each

mental health service-user – and many people with experience of mental health problems who do not use services – to find the appropriate support that works for them. This support, be it medication, alternative and complementary therapies, or support that also recognises their spiritual or religious perspective, may be quite different from that which works for the person standing next to them.

This means that user-led research tends to be qualitative. It puts a value on the range of people's personal experiences and recognises the importance of the context – so focusing more on holistic services.

But the difference between the experiences of 'professional' researchers and mental health service user-researchers should not be ignored. The increasing emphasis on extreme professionalism in mental health services has meant that there is, increasingly, a perceived gap between the professionals, who 'know' based on exhaustive research and years of training and education, and mental health service users, who may have interrupted training, education and careers. This project should help people from both sides of the divide to face this question and, crucially, to begin to redress the balance of expertise.

Strategies for Living user-led research pilot programme

In the pilot programme, research proposals were selected to reflect the conclusions of the Mental Health Foundation's earlier *Strategies for Living* research (Faulkner, 1997; Faulkner & Layzell, 2000), itself led by people with personal experience of mental health problems and/or of using mental health services. Both large-scale research projects looked at the ways in which people manage their own mental health and brought out the importance of personal support and accepting relationships, the impact of alternative and complementary therapies, and the importance of religious or spiritual beliefs in people's lives.

The first six small-scale user-led research projects, run over the last two years, reflect these concerns, focusing on:

- the impact of auricular acupuncture
- training mental health services users in giving and receiving massage
- the use of drop-ins
- the importance of the mosque to the mental health of Moslem men
- user groups as a self-help technique
- increasing access to alternative choices through mainstream mental health services.

To support the projects, a number of training sessions were run through the course of the project, in addition to one-to-one support from the project officer at the Mental Health Foundation. Structured training sessions covered:

- introduction to research
- interview skills and questionnaire design
- focus groups
- project updates and empowerment discussion
- introduction to data analysis
- report-writing.

Funding from the National Lottery Charities Board will now enable the Mental Health Foundation's *Strategies for Living* project to recruit three research support workers based in London, Glasgow and Cardiff, each of whom will support around five user-led research projects. A number of lessons were learnt through supporting and managing the first small research projects, which will affect the running of the new programme.

Empowerment

The recruitment of the pilot user-led community research projects was achieved by advertising the programme through mental health service user and survivor networks and newsletters. A primary

requirement was, not current research experience, but experience of using mental health services. Each research project not only provided evidence about services, but also helped to train and empower service users. Interviews with researchers at the completion of the project brought forward the following responses.

'People with mental health problems, a lot of them anyway, are very keen to find real work opportunities, or to get into some sort of training that would prepare them for real work – even if it is voluntary in the first instance... So many people feel that research is done to them... it's all part of the rising tide of empowerment really, people feeling more in control of what they do...'

'I've gained a lot of confidence and lots of competence in research, lots of experience, typing skills (they paid for my typing lessons) a sense of purpose, lots of research skills, which is quite an achievement really. And the feeling that I have actually benefited the women, that's the personal satisfaction, that's the real value.'

In each user-led project, it was not only the core researcher who felt these benefits, but also a number of other people who had been involved with the research project and various different processes and techniques.

Identity

However, a number of interesting questions around identity were raised.

Despite the voluntary nature of the contract between the Mental Health Foundation and the (unpaid) researchers, each researcher also had to recognise that, while carrying out the project, participants would see them as holding power – even if it did not necessarily feel like that.

The project also encouraged researchers to recognise that their own identity would affect the project. The age, race, gender and class of the researcher and the

decision whether or not to self-identify as a mental health service user all affected the way in which participants interacted with the research process. A key conclusion of the project was that there was rarely, if ever, any right or wrong answer on this question, but that the important thing was to recognise the potential influence and be honest in writing up the research project.

Supporting user-researchers

The majority of problems and difficulties experienced were the same as those that any researcher experiences: recruiting participants, attendance, drop-out rate, writing reports, meeting deadlines. However, one of the learning points from the initial project was the need for better support – recognising that many of the user-researchers had fewer resources to call upon than many of their contemporaries in academic institutions.

A number of researchers on the original project, particularly those working on their own, experienced difficulties through sensitive and emotionally challenging one-to-one interviews – something usually dealt with by other researchers through formal debriefing sessions. The need for local support was covered by the *Strategies for Living* team in early discussions with each researcher, as part of the process of recognising what support could be provided, by phone, during office hours, and where there would be additional personal needs. Being able to access appropriate support that recognised the researcher's religion, culture or gender, for example, was seen as particularly significant.

Reviewing these experiences has meant that a number of factors will receive particular attention when agreeing new research proposals.

- Increased emphasis will be placed on proactively strengthening links between local support networks and mental health projects and the national *Strategies for Living* programme, to enable user researchers to find appropriate support more easily.

- Research proposals from a single individual working in isolation rather than within a project will be explored together with the possibilities for the researcher to receive appropriate and continuous local support.

The participants valued the training sessions held throughout the project and, in order to develop them further, a number of additional sessions have been identified for the new project, focusing not on the specific processes of research but on core skills and practices:

- ethics, particularly confidentiality, payment, how to manage endings with participants, and the importance of providing feedback on results to research participants
- assertiveness
- time management.

In order to strengthen the training sessions, the *Strategies for Living* team will be identifying a number of external people with specific skills who may be able to provide one-to-one support on difficult areas such as writing reports, as well as leading training sessions.

There are also plans to develop a nationally accredited certificate for mental health service users engaged in research. The certificate, which will be informed by the Mental Health Foundation's development of the recent RVQ (Related Vocational Qualification) in community mental health care, would be designed specifically for people without formal qualifications in research and would help set the standard for the future.

Timing and flexibility

Of prime importance in user-led research is the ability to retain flexibility over deadlines and to recognise that, at particular points of the project, researchers, or indeed programme leaders at the Mental Health

Foundation, may be unwell. This flexibility was built into the programme from the very beginning, but the experiences in the initial project have dictated that more flexibility should be built into the process for subsequent research projects, particularly during the report-writing stage.

Phase 2 – *Strategies for Living* UK network

Building on the experiences of the initial programme, the national *Strategies for Living* user-led research project has already started development work and will be recruiting three research support workers in spring 2001. From here it will move on to deciding research proposals, allocating grants and beginning the research and training process.

It is estimated that around 1,000 service users will be involved directly and indirectly in the research projects. The Mental Health Foundation's experience indicates that those involved will benefit through improved self-esteem, learning new skills and potentially moving on to other training or employment.

The research will focus on holistic approaches to mental health, and by focusing on areas such as support groups, self-management, and complementary therapies for example, will provide valuable evidence for local service planners who want to provide a range of effective and appropriate services.

The research should address the funding problems continually experienced by some of the services that people with mental health problems find most helpful (and which may help to prevent them reaching crisis point) caused by lack of firm evidence to support their work.

The long-term results should include a different shape for mental health services.

For more information on the project, contact Alison Faulkner or Vicky Nicholls at the Mental Health Foundation's Strategies for Living programme, 20/21 Cornwall Terrace, London, NW1 4QL or Tel 020 7535 7400 website: www.mentalhealth.org.uk

References

Barnes, C. & Mercer, G. (1997) *Doing Disability Research*. Leeds: The Disability Press.

Beeforth, M., Conlan, E. & Graley, R. (1994) *Have we Got Views for you: User Evaluation of Case Management*. London: The Sainsbury Centre for Mental Health.

Faulkner, A. (1997) *Knowing Our Own Minds*. London: Mental Health Foundation.

Faulkner, A. & Layzell, S. (2000) *Strategies for Living: A Report of User-led Research into People's Strategies for Living with Mental Distress*. London: Mental Health Foundation.

Mental Health Foundation (1999) *A DIY Guide to Survivor-Led Research*. London: The Mental Health Foundation.

Nicholls, V. (2000) *In Good Faith: A Resource Guide for Mental and Spiritual Wellbeing*. London: The Mental Health Foundation.

Rose, D., Ford, R., Lindley, P., Gawith, L. & The KCW Mental Health Monitoring Users' Group (1998) *In Our Experience: User-Focused Monitoring of Mental Health Services in Kensington & Chelsea and Westminster Health Authority*. London: The Sainsbury Centre for Mental Health.

Events Diary

Title: Environments of Care for Older People
Pavilion in association with The Health Advisory Service
Date: 8 March 2001
Venue: New Connaught Rooms, Covent Garden, London
Contact: Pavilion

Title: A Safer Place: combating violence against social care staff
Pavilion in association with Community Care
Dates & Venues: 9 March 2001 – The Hilton Brighton West Pier Hotel, Brighton
13 March 2001 – Holiday Inn, Bristol
22 March 2001 – Race Course, Chester
27 March 2001 – Race Course, York
Contact: Pavilion

Title: Mentally Disordered Offenders: providing mental health services in the community
Pavilion in association with Turning Point
Date: 15 March 2001
Venue: Manchester Town Hall
Contact: Pavilion

Title: Overcoming the Blocks to Direct Payments
Pavilion in association with Bright Enterprises and Independent Living Advocacy (Essex)
Date: 28 March 2001
Venue: ORT House Conference Centre, London
Contact: Pavilion

Title: Developing Rehabilitation Opportunities for Older People
The King's Fund in association with Pavilion
Date: April 2001
Venue: Central London
Contact: Pavilion

Title: Professional Regulation and the Protection of Vulnerable Adults
Pavilion in association with Salomons
Date: 24 April 2001
Venue: London Voluntary Sector Resource Centre, Holloway Road, London
Contact: Pavilion

Title: Resettlement – an Inclusive Learning Process
Pavilion in association with Glasgow Simon Community
Dates & Venues: 9 May 2001 – Glasgow
21 May 2001 - London
Contact: Pavilion

Title: All Together Now: creating partnerships to implement the Learning Disability White Paper
Pavilion in association with Tizard Centre
Date: 9 May 2001
Venue: London Voluntary Sector Resource Centre, Holloway Road, London
Contact: Pavilion

To book any of these events:
Tel **01273 623222**, fax **01273 625526**,
email pavpub@pavilion.co.uk
Book online at www.pavpub.com



If you have any events that you wish to be included in the events diary, please forward brief details (title, date, venue, contact name and number) to the Journals Marketing Executive, Marketing Dept, Pavilion Publishing, tel **+44 (0)1273 623222** fax **+44 (0)1273 625526** or email carriet@pavpub.com.
(we regret we cannot guarantee inclusion of your events).