

strategies for living

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the
Mental Health
Foundation

ISSUE 20
Autumn 2003

Employment & Benefits
page 2



*Hospital based
research*
page 4

Ways of coping
page 5



Dancing for Living
page 6

Relationships
page 7

Welcome to the Strategies for Living newsletter, incorporating news on survivor/user led research, adult mental health and user empowerment.

findings

We are proud to devote this issue to the findings from the user-led research projects, investigating different aspects of coping with mental distress, we have been supporting over the last three years. Due to space limitations we have only been able to highlight key themes and findings that arose from these small-scale studies, but we hope these give an insight into the important issues that were investigated. Please see the back page for details of how to get more information about these projects and our report on our experience of supporting the projects.

the researchers

The commitment of the researchers during this process has been amazing and we would like to fully applaud their perseverance in working through the many challenges in undertaking the research. It was always our intention that the process of being involved in the research would be as important as producing robust findings. The researchers came from a wide variety of backgrounds, most with little or no research experience. During the training process the researchers developed (or rediscovered) their skills and many, in an evaluation of their experience of working with Strategies for Living, commented on how their confidence has increased. Many researchers also commented on how much they got from meeting and working with others, including both fellow researchers and participants. The importance of supportive relationships is a theme that runs across the findings of many of the projects.

strategies

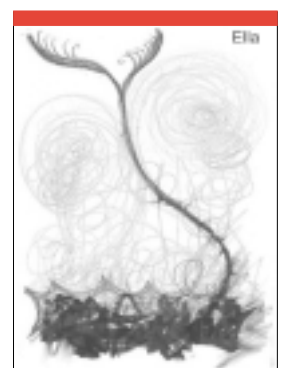
Although the picture painted by the findings is a complex and sometimes bleak one, the plethora of self-help and healing strategies has been inspiring. These underline both the interdependence of humanity in reaching across to one another at times of need, and the amazing capacity of individuals to find ways of coping or living with the extremes of experiences of distress. We hope that the experiences and findings of these projects will motivate, encourage and inspire others to try both old and new strategies for living. ■



Flow by May



Staccato by Stella



Moving from being stuck
by Ella

The artwork above and where credited elsewhere in this newsletter is by participants in the 'Dancing for Living' project.



employment

'stigma had contributed to loss of occupation'

There were three supported projects investigating issues related to work, occupation and benefits:

- the 'Life's Labours Lost' project, which explored people's experiences of loss of occupation through mental health difficulties and subsequent regaining of occupation in Bristol (56 participants);
- the 'Working on Up' project, which investigated the experiences of people with mental health difficulties regaining employment after a period of being unwell in Aberystwyth (10 participants); and
- the 'Healthy Benefits' project, which investigated service users' experiences of accessing the benefits system and benefits advice in Glasgow (55 participants).



By Eileen (Dancing for Living)

'a lot of people had been given no support at all'

stigma

In the 'Life's Labours Lost' project, stigma had contributed to loss of occupation. In both this and the 'Working on Up' project, stigmatisation of mental health problems was reported as being a serious barrier in returning to work.

Disclosure of mental health problems was an issue for participants in both projects. In the first, a significant number of people were too

embarrassed to return to work after having mental health problems, and there were substantial fears of harassment in the workplace. In the second, several interviewees reported feeling unable to disclose their mental health experience in a workplace because of potential stigma and discrimination.

Ignorance about the nature and effects of mental health problems appears to have been behind much of the reported stigma and discrimination. This was shockingly widespread among employers, benefits agencies and job centres. Many participants in all three projects reported negative experiences and attitudes, including dismissive and sarcastic approaches at benefits-related medicals.

support

In all three of these projects, participants reported difficulties due to a lack of support or flexibility. This ranged from problems with everyday practical tasks such as filling out benefits forms through to enormous barriers created by the inflexibility of the benefits system.

This inflexibility was widely experienced as assuming people were either too ill to do any work, or well enough to do any type of work and

full time hours. In the 'Life's Labours Lost' project, changes to the benefits system were called for by the second highest number of people, when stating what would be helpful in finding work. Being able to do part-time or voluntary work to start with, was important in both this and the 'Working on Up' project, where inflexible hours and times of work made it very difficult for some interviewees to be able to stay in work.

Over half of respondents in the 'Life's Labours Lost' project had not been able to continue the work or study that they had taken up since their initial loss of occupation. This caused further damage to people's confidence and self-esteem.

Although 68% of participants in this study did now have some kind of occupation, they had less responsibility, worked less hours and were either unpaid or on much lower pay. Despite this marginalisation they found being in occupation satisfying and helpful.

Respondents gave by far the highest priority to provision of support when asked what would help them find meaningful occupation. In the 'Life's Labours Lost' project, a lot of people had been given no support at all.

and benefits

And, of those who had received help, usually from family or friends, health professionals, or support groups, about one third of the 'help' received was not effective. When asked what most helped them get back into occupation, most people emphasised their own efforts and qualities.

The need for general emotional support to cope with their mental health problems and rebuild their lives was emphasised alongside the need for specialist guidance, advice

and information about occupations.

benefits advice

In the 'Healthy Benefits' project, people had received advice from a wide range of sources, including social workers, advice centres, nurses, support workers, Citizens Advice Bureaux, benefits offices, family and friends. However, views of the usefulness of this help varied widely, with much higher ratings given for welfare rights services and mental health workers than for benefits offices, where

help was rated as poor or very poor by over half of respondents.

People had received help with a number of aspects of the benefits system, in particular form filling (64%); support through the claims process (33%); and helping to understand or explain the importance of particular symptoms (22%). Almost half of respondents, however, said that they thought there wasn't enough benefits advice available for people with mental health problems. ■

'the usefulness of benefits advice varied widely'

racism

In the 'Rainbow Nation' project investigating issues for African and African-Caribbean women in Bradford (6 participants), most of the interviewees were resigned to the fact that racism was an everyday occurrence in their lives. Some women had been given multiple-diagnoses. This was felt to have happened because when African and African-Caribbean women are first in contact with mental health services they are often perceived as being in a different category of mental distress: *'They tried to pin schizophrenia on me'*.

Several participants had experienced racial abuse from neighbours, from some staff in mental health services, particularly hostels, and from some service users. Women's

hostels were experienced as not responding to people's diverse cultural needs.

support

Interviewees called for culturally aware mental health support for Black women, and funding for Black-led organisations that deal with Black women's mental health issues and offer outreach support. The women urgently needed access to information about the different types of mental distress that they experience and to be guided to services or support groups that may benefit them.

Participants identified practical issues that could improve life in hospital, such as having translators for people from the African continent and the 'Voice'



Karan Essien – Researcher

newspaper being available on the wards.

Racism was also an underlying experience that had influenced the forming of negative beliefs and fear among some interviewees in the project in the south of England which explored people's strategies for coping with 'unusual' beliefs (11 participants). Beliefs included being persecuted, pursued, or a fear of contamination. ■

hospital settings

Two of the supported projects were hospital-based: 'Coping Strategies in Psychiatric Hospital Settings' in Northern Ireland (55 participants); and 'Leave for Patients detained under Sections 37/41' in a secure setting in Wales (5 participants).

'hospital routines were seen as more important for staff than addressing patients' needs'

Relationships between staff and patients were a key theme in both of these projects. The research in Northern Ireland found that staff and patients rarely engage in a relationship based on therapeutic interactions. Patients saw the role of staff as primarily prescribing medication and ensuring that rules were adhered to, and hospital routines were seen as more important for staff than addressing patients' needs. Meals were served at set

times and medication administered at strict intervals: *'Everything is rushed. Marched in, get your medication, on to the next person. You have no time to think about what is going on.'*

For the research in the secure hospital setting, trust was a big factor determining whether patients felt they could talk to staff, particularly at the start of their stay in hospital before they knew the staff well. Interviewees had concerns about information being passed on to other staff or patients.

power

The amount of power that staff had over patients emerged strongly from both projects: including the strict

adherence to hospital routines and a lack of information-sharing about many aspects of decision-making such as timing of discharge. Clearly for patients detained under sections 37/41 there is a significant degree of power over almost every aspect of patients' lives over a long period of time, and there was a range of views voiced about how supportive various staff had been in this context. In the Northern Ireland-based research, there was overall dissatisfaction with the amount of energy put into supporting patients to develop their own self-help strategies.

lack of control

Participants in the research in Northern Ireland felt they had little control over their circumstances, and thus had a sense of powerlessness. This was echoed in the research in the secure hospital setting, where lack of control was a significant experience and feeling for patients. Accepting this lack of control was sometimes seen as a positive strategy to help patients cope with their situation. Some interviewees described how they had no say about leave; that there was a lot of waiting to hear whether or not they could have leave; and not knowing what

would happen if they broke the rules.

activities

In Northern Ireland, research participants said that there were not enough therapeutic activities. There was a lack of access to activity rooms, which were



By May (Dancing for Living)



Lyrical by Jay (Dancing for Living)

locked for long periods of time. Although this was in the context of a lack of staff, which people were very aware of, the net result was an under-stimulating and non-therapeutic environment. In the secure hospital research, participants thought that taking part in occupational therapy sessions was viewed in a positive light by staff, possibly leading to a greater likelihood of obtaining leave. However, some interviewees thought that the sessions were not interesting for everyone and that the lack of choice in whether to attend was unfair. ■

ways of coping: self-help

In the Northern Ireland research (see previous page) there was a strong sense of camaraderie with other patients, which helped counteract feelings of stigma and isolation.

Ways of passing the time and coping with stress whilst an inpatient included the inevitable television. Other examples given by focus group participants included:

- reflection/time out/private space and escapism including listening to music; the glow of the tea machine, looking at a picture, crying, and looking out of a window
- physical relief such as smoking, comfort eating, venting frustration by kicking objects and shouting, and, for two people, even self-harm
- minimising the effects of despair including marking time from day to day, and
- keeping self-harm and suicidal thoughts in safe personal boundaries.

People also had pastimes and ways of keeping mentally and physically active such as walking, ironing and washing, self-grooming, and helping others to run the ward.

support

In the Black women's project (see page 3), the women identified the following techniques for coping at times of mental distress: window shopping; listening to music; writing problems down; keep going for the children; coming off medication; having a supportive partner; and support from family and friends.

In the 'Unusual Beliefs' project (see page 3) participants identified strategies such as:

- finding a particular 'mindset' such as 'staying in control when feeling paranoid', and trying to ignore beliefs. Or sometimes accepting them.
- 'self-talk' such as reassuring themselves or

reasoning with themselves.

- challenging themselves i.e. shortening rituals to convince themselves there would be no terrible consequences.
- using protection strategies including wearing protective clothing to help them feel safe from attack, and taking showers at a public pool because they believed their flat was contaminated.



Stillness by May (Dancing for Living)

- distraction or alternative focus - doing everyday tasks such as cleaning or shopping and other activities such as walking and listening to music.
- relationships - feeling accepted or having someone who had similar experiences to talk to. ■

self-help groups for people who self-harm

Discrimination and stigma were also experienced by those who took part in the 'Self-help groups for People who Self-harm' project in Nottingham (34 participants).

Here people described negative attitudes from mental health professionals, and staff in accident and emergency wards, as well as feeling that friends and family were upset or shocked by their self-harm.

Attending a group meant they were able to build relationships with others in a safe and supportive environment, as well as gain new skills, find out information about self-harm

continued overleaf

'the groups provided help that the participants did not receive elsewhere'

dancing for living

The 'Dancing for Living' project (19 participants) showed the value of creativity and pleasure in the lives of people who experience mental distress.

The women who took part in this research described 5

Rhythms* dance as helping them release powerful emotions, and it gave them a feeling of liberation and a sense of

relief:
'The more I dance what I feel, I change from being stuck to start with.'

They described being able

to face feelings that they had blocked for a long time. Not all the women described such powerful transformations or emotional release - however this was a personal coping strategy that also provided the participants with good physical exercise and fun.

The women felt more energised and some women described how 5 Rhythms dance had taught them to look after their bodies better and deal with things

** A form of dance developed by Gabrielle Roth, that moves dancers through 5 rhythms: flowing, staccato, chaos, lyrical and stillness, as they dance their feelings to the music.*

within their limits. For many, although 5 Rhythms dance was not a therapy, it was able to be used therapeutically and could be a resource to look after themselves better, and even as a form of healing. The dance did not always need to be done in a group environment and the women could dance at home to their own choice of music and rhythms.

Respondents also identified issues such as the need for the dancing to be low cost or even free, possibly in psychiatric settings, with people who had already been introduced to it and trusted it. It was felt that the dance should not be used at a time of feeling very distressed. ■



Sarah Cook, Karen Ledger and Nadine Scott – Researchers

self-help groups for people who self-harm

continued from previous page
and also reduce their self-harm, although this was not a reason for attending a group. The groups provided help that they did not receive elsewhere.

Only two people described attending a group as unhelpful, because of not feeling accepted or feeling different to others in the group, although both of these people reported having learned new skills that they were able to use in another group they were

now part of.

concern

For others the most difficult factor in attending a self-help group was their concern for others in the group:

'I guess sometimes when people get really distressed and although you do as much as you can to help, they're going to go away and sort of, continue to be distressed ... you sort of think oh I should have done this and that and you start beating yourself up about it really, so it can have

a bit of a negative effect sometimes.'

Most groups had no funding, and obtaining funding was difficult for a number of reasons. Groups were not able to demonstrate the effectiveness often required by funding agencies in relation to self-harm reduction. The pressures of finding funding as well as spending time advertising the group, allaying professionals' fears about the group, meeting new members, and organising venues and meeting times, meant group leaders and facilitators ran the risk of 'burn out'. ■

'obtaining funding was difficult for a number of reasons'

relationships

The centrality of relationships, which has been highlighted in our previous work, was underlined by the findings from a number of the supported projects:

- Dynamics of relationships with other patients and staff in hospitals. In acute wards in Northern Ireland (see page 4), the support offered by other patients was important, helping people to know that they are not alone in their experiences, supporting one another to develop self and mutual help strategies, and encouraging a sense of belief in and hope of recovery.
- In the 'Access to Benefits'

project (see page 2), a key role was played by benefits advice and support workers in empowering people to gain access to their entitlements.

- In the 'Self-help groups for People who Self-harm' project (see page 5), more than two thirds of respondents reported that they felt valued, accepted and not judged by other members of the groups. Making friends and helping others were also key findings in this study.
- In the 'Dancing for Living' project (see previous page) the importance of a safe space in the women's lives where they felt accepted however they moved or whatever emotions they expressed.

caring for someone with bi-polar disorder

The project based in Gwent that explored the needs and experiences of unpaid carers of people with a diagnosis of bi-polar disorder (BPD), centred on relationships (13 participants).

Many carers reported stress, sleeping problems, anxiety and depression. The carers were asked how they coped when the person they cared for was ill. Many said having people to talk to was a major part of their coping strategy. Some talked about contact with other

carers and the overwhelming need to share experiences with them; over half commented on the outstanding support they received from family and friends; and the vast majority (92%) stated that friendships were very important and that they relied on friends for help and support. The findings suggest that friends and family were more likely to be supportive if they had knowledge about BPD.

Sometimes other people's fear and ignorance led to

Yet sometimes even in this environment it could still be difficult to show emotions or it could be difficult to be close to people when people were not used to this.

isolation

Interviewees in the Black women's project, and again in the 'Coping with Unusual Beliefs' work (see page 2) highlighted the pain of isolation. In these projects some participants felt separated from and afraid of mainstream society, and in the later project, developing sometimes quite complex and sophisticated techniques for making themselves feel safe enough to venture out of home. ■



Strategies for Living staff (current & past), researchers and advisory committee members

the loss of friendships and family relationships. A number of participants reported isolation as a problem.

Other key findings identified in this project were: the negative effect that the majority of working carers felt that caring had on their work; all carers felt they needed more information around BPD; and the fact that most of the participants stated that they had very little or no support from mental health services. ■

advocacy

There was a strong belief in advocacy as restoring the balance of power, by allowing the client to take their power back from the system among the seventeen participating groups in the project looking at mental health advocacy in Wales. This was seen to be linked to taking control and recovery.

Other key findings included:

- Lack of resources including funding, office space, staff, training and equipment was a huge problem. Many schemes had only one worker and fundraising became a distraction from actual

advocacy provision.

- Huge variations across schemes in many areas such as funding, management and policies. A common structure could reduce isolation and associated stress.
- Independence - Although it was felt essential that advocacy services were independent of other providers in order to gain the client's trust, there were varying views on acceptable levels of independence.
- User-led - Many participants felt that advocacy services would ideally be user-led but this was considered to be very difficult. All schemes

encouraged people with personal experience of distress to be involved as staff, volunteers and trustees, and saw this as an essential contribution.

- Mental Health Bill - Concerns about the implications for advocacy of the proposed new Mental Health Act included: the lack of advocacy provision to deal with the expected increased demand under the new Act; uncertainty about the meaning of 'a specialist advocate'; and the fact that obligatory advocacy would make advocates part of the system and cause a loss of client trust. ■

Please contact us if you would like to join our mailing list or would like more copies of this newsletter for local networks.

further information

Individual project reports

Both summary and most full reports from the projects featured in this newsletter will soon be available on the Foundation's website at www.mentalhealth.org.

For paper copies of individual summaries please send an A4 stamped addressed envelope (20p stamp for up to 2 reports, 34p for up to 4, 46p for up to 6 and 56p for up to 8), indicating which reports you would like, to Strategies for Living.

For information on how to obtain full reports contact Strategies for Living.

Surviving user-led research: reflections on supporting user-led research projects £30 (£15 to survivors and service-users)

This report describes the complexities, realities, challenges and limitations of user-led research as experienced by the Strategies for Living II team. It also outlines the lessons learned from these experiences, uses examples and stories to illustrate points, and includes tips and recommendations. It is intended as a valuable resource for anyone, who has some familiarity with the field, and is considering carrying out or supporting user-led research.



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strategies for living is edited by Stephanie Wells

Print & Distribution by L&T Press, Luton.

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Registered charity
no. 801130

Company limited by
guarantee number
2350846

Strategies for Living is
supported by:

COMMUNITY FUND
Lottery money making a difference