

strategies for living

www.mentalhealth.org.uk



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

welcome.....

Toby Williamson came into post as Head of Strategies for Living (Adult Mental Health & User Empowerment) in June. Toby introduces himself inside and will also be presenting the 'Welcome' session at the Big Alternative Conference on 3rd October.

new chief executive

We also welcome Andrew McCulloch, previously Head of Policy at The Sainsbury Centre for Mental Health, who has replaced Ruth Lesirge as Chief Executive at the Mental Health Foundation

draft mental health bill

The Mental Health Foundation is part of the Mental Health Alliance (MHA), a coalition of over 50 organisations who share common concerns about the Government's proposals to reform the Mental Health Act (1983). The MHA are opposing the bill primarily due to concern over the extended powers for compulsory detention/treatment outlined and the widening of the definition of mental disorder. A mass Parliamentary lobby is planned for mid-October, visit www.mentalhealthalliance.org.uk or telephone: 020 8215 2323 for details.

the future

The Strategies for Living Team recently had an awayday during which we discussed the future of our work, which includes S4L supported projects and the Advanced Statements project. Some of the proposals to come out of this were: a consultancy network with a user-survivor research website; training and dissemination of research findings; and undertaking/supporting further Strategies for Living projects. ■



"women s



Artwork by Alison Hilton

Last year Resisters, a Leeds based women and mental health action group, commissioned research into women's experiences of mental health services in Leeds in order to identify areas for change. Resisters was set up in 1993 and consists of women who have experienced mental distress and

women who work to support such women. The group aims to provide a voice for women who have not received adequate

support either in prevention or recovery, and to bring about change in the mental health system.

The research was conducted by a team of women service users, co-ordinated by Yvonne Prendergast (Echo Training and Consultancy). Eighty-seven women were consulted for the report, some individually and some through group work.

involvement

The research was based on the belief that women are able to define their own problems and state what they need and want in terms of support. Women service users were actively

involved in every stage of the design, delivery and analysis of the research, and it was through this that we were able to develop a research process that was respectful of the women we then consulted.

The women we interviewed described a range of experiences and issues that contributed to their distress including:

- Pressures of day to day life
- Living with oppression
- Domestic violence
- Sexual abuse
- Life events
- Biology

The women interviewed had used a range of services, and described what they had found helpful and unhelpful.

I feel proud to have been involved in this project, I've gained more confidence in myself and I feel stronger too

views of the research team

"Being an interviewer with the research project has been a unique and incredibly rewarding experience. I have met some amazing women and have been touched by their bravery and openness in speaking out about their experiences, some of them horrifying, all of them humbling."

"I feel proud to have been involved in this project, I've gained more confidence in myself and I feel stronger too, from using the telephone to meeting new people. Being treated as a normal person, leaving the badge at home saying I've got a mental illness."

"On a personal level I have gained a lot, I have met some brilliant women and also have had fun and felt supported throughout. This project so far has seemed to run very smoothly and I feel that this has been the most supported project I have been involved with."

"It is not enough to say improvements have been made and therefore campaigning for change can be relaxed. I believe the results of this research project will illustrate there are still many people whose experiences of mental health services show that there is much work to be done to ensure that expected standards of care are consistent for patients, despite differences of gender, race, age, sexual orientation, economic circumstance or geographical location"

Speak out"

Ria Foster

The difficulty in finding information about appropriate services was described by women of all backgrounds, and the key role GPs can play in providing this information (or not, in many cases) was highlighted. Day centres and talking treatments were services that were found to

little say in the treatment received were key themes.

"I was anorexic. My Doctor said, "You just need to put on some weight, get married and start cooking for your husband" - and that was his diagnosis, of what I needed."

"Other women and other men, mental health users, they're the ones who really help." "A

launch

The report was launched in June at the West Yorkshire Playhouse and was presented through a mixture of talking, drama and poetry devised by a team of women from Resisters and the Yorkshire Women's Theatre.

The result was a powerful, moving and brave presentation of the issues.

Representatives from the voluntary and statutory sector publicly undertook to address the issues raised in it.

Women Speak Out is an inspiring, powerful and significant piece of research, of great importance to women using mental health services and service providers not only in Leeds but nationwide. The women involved have clearly shown the ability to define for themselves what they need and what they want. In the words of one of the research team members, "Hopefully you will all not only listen, but you will hear, and you will act". ■

Hopefully you will all not only listen, but you will hear, and you will act

what women want

"I suppose just to be treated with respect."

"Places being open 7 days a week"

"There should be someone who speaks my language wherever I go".

"Certainly at the outset for the message I get to be a message of: this is a blip, recovery is what will happen. Not to be written off at the outset by them. Because then you write yourself off too. What I say to people is, think about recovery. First and foremost, think about recovery"

"The main thing would be more female-only services."

be helpful by the majority of women who had used them. Gaining support from other service users also proved valuable to many women. Services that were generally found to be unhelpful included; seeing psychiatrists, medication, inpatient hospital treatment and ECT. Not being listened to, being treated disrespectfully and having

mad Black woman - nobody cares, or they're frightened. All I wanted was help."

" I did tell one GP about my step dad, and he sent me off with medication. You shut yourself off then and think, oh well, I did tell someone and what's happened."

"The psychiatrist showed no respect, respect meaning valuing another human being and their experience."



Artwork by Lynda Bradley

For more information about Resisters or the report, please contact them at: Resisters, c/o Leeds Mental Health Advocacy Group, Centenary House, 59 North Street, Leeds, LS2 8AY

Or email: resisterz@yahoo.co.uk

a hard act to follow...

Toby Williamson

...but exciting nevertheless to have started in post as Head of Strategies for Living at The Mental Health Foundation, following Alison Faulkner's departure.

Having been involved with mental health services since 1983 I have always been interested and excited by the importance and variety of work done by the user/survivor movement. I had therefore been aware of the Strategies for Living programme of user/survivor-led research since it began in 1997 and now I'm in post I very much hope to build upon the success it has achieved, as well as promoting and developing

other areas of work in adult mental health that MHF can be involved in, such as the Advance Statements project in Bradford.

experience

Before coming to the Foundation I worked for nearly 7 years at Hammersmith & Fulham Mind in West London where I was the co-ordinator of an outreach team for people with very severe and enduring mental health problems. During this time I also delivered training on behalf of the Sainsbury Centre for Mental Health. I have also worked for a housing association and in the statutory sector doing a variety of jobs in community mental health, especially in

the field of housing. My experience of research has been more as a subject of it than as a researcher although this, combined with studying social sciences in higher education (which for a time coincided with my own personal experience of mental health difficulties) has hopefully given me a good grounding in what it's all about. What I look forward to most in my new post is the opportunity to work with user/survivors, the Strategies for Living team at MHF, and mental health services themselves, to develop new approaches and ways of thinking to promoting mental well being and reducing mental distress. ■



Toby Williamson
Head of Strategies for Living (Adult Mental Health & User Empowerment)

cyber networking

Strategies for Living and the Mental Health Foundation support various ways for people to communicate and share ideas around topics related to our work.

Bulletin Boards - where you can post and respond to messages under the following topics:

- Problems and Conditions
- Strategies and Treatments
- Attitudes and Discrimination
- Children and Young People
- Adults in Later Life
- Miscellaneous

Email Research Discussion Forum - an email discussion group aiming to bring together mental health service users and survivors who are undertaking or interested in research into mental health

issues. By sending and responding to messages to all the other subscribers to the forum, you will be able to ask questions, share information, find answers,

and share ideas with others doing similar work. You can join the forum and access the bulletin boards on our website at www.mentalhealth.org.uk. Go to 'Tell Us' and click on the relevant heading. ■



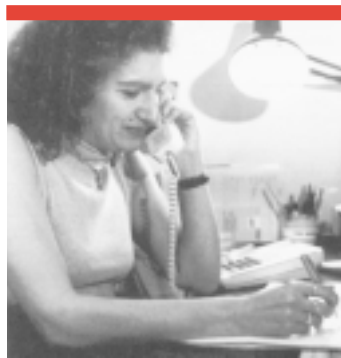
contributions welcome

If you would like to contribute to this newsletter e.g. an article, poetry or illustration, please get in touch.

POPAN prevention of professional abuse network

Sukey Montford

At the heart of any professional caring or therapeutic relationship is trust - trust that the professional will help those they care for. This



trust is vital because of people's vulnerability when

Professional abuse involves one of the following:

- Betrayal of patient's trust
- Failure to maintain professional boundaries
- Exploitation of patient's vulnerability

Abuse can be:

- sexual, including inappropriate touching
- emotional, including breaking of confidentiality, creating a dependency, or seeking to dominate or humiliate the client

confused by their experiences. For some the event may be recent, for others the abuse may have happened some years ago, or they may still be in abusive relationships. People often need space to talk through in confidence what has happened, understand how the professional relationship was breached and look at ways to begin to address some of the issues raised by the abuse. POPAN neither encourages or discourages people from making a complaint (for

David went to see a counsellor after the death of his mother. On the third session the counsellor herself broke down crying saying how the death of David's mother reminded her of her own mother's death which she had not been able to come to terms with. David was left feeling very confused and unsupported.

Jane suffered severe post-natal depression after the birth of her third child. She was assigned to a male CPN. After he had visited a number of times she asked him for a hug. These hugs became regular and developed into a sexual relationship. The CPN made Jane promise not to tell anyone what was happening as he said he would be in serious trouble with his employers.

they seek help from professionals such as a doctor, counsellor, social care worker, or other health worker. As a result these relationships are prone to exploitation and abuse, sometimes unintentionally, with often devastating effects for the patient. POPAN is the only charity dedicated to working with people who have been the victims of professional abuse.

- physical, including angry or threatening gestures
- financial, including encouraging payment for a service such as therapy when the client is no longer benefiting.

Abuse can happen once, every so often or on a regular basis over a long time.

Most people who have been abused by a professional are very distressed and

example to a NHS Trust, voluntary organisation or professional body) but if this is what somebody wants to do, it can provide advocacy support. POPAN's support line is for anybody who is concerned about an incident of professional abuse. This could relate either to themselves or to someone they know or are working with. The line provides information, support and advice. ■

Abuse can happen once, every so often or on a regular basis over a long time.

Most people who have been abused by a professional are very distressed and confused by their experiences.

POPAN support line is open from 10.00am to 4.00pm Monday to Friday. The number is 0845 4 500 300 (charged at local rate).

what's happening with our supported projects?

Two of our supported researchers give updates on their projects

5rhythms dance

Karen Ledger



Artwork by Nadine Scott

My project is about evaluating the impact of 5Rhythms dance and its effect on women's mental well being. It is slightly different from the other research projects in England

in that we actually participated in the dancing as well as the research. This was quite a leap for me, as I had never danced in my life. 5Rhythms dance basically consists of five different rhythms to dance to. The idea is to start with a gentle rhythm then build up to a

faster more loud rhythm and then to calm down again. There are no set rules for how you dance except that if you have a teacher to take the class, which we did, then she can suggest ways that you might like to move.

support

From the very beginning the Strategies for Living Project has supported me in my research work. Virtually every month all of the English research projects meet up in one of our home towns, where we receive training in different areas of

research, such as ethics or how to put together a questionnaire.

We have completed the four dancing sessions at which we conducted a questionnaire, peer pair interviews and transcribed focus groups. We are now gathering all the information together and analysing it and will have the completed report ready for publication next year.

I'll finish by saying how much I am enjoying doing the research and hope to do more in the future. ■

living with self-harm - we need more than a sticking plaster

Nicola Williamson

The project I am working on is about finding out how people who self-harm are able to cope with their condition. I would like to examine what helps and what could be improved for this condition and also to promote a more holistic approach. I am a local service user and a self-harmer.

For this research I am distributing questionnaires and interviewing people who self-harm and those working alongside those who self-harm.

experiences

The questionnaire will be distributed through the local resource centres and mental health groups. I will be asking a small number of people to talk to me in more depth about their experiences. My research findings will be sent to service providers in my area and possibly beyond. The final report will be published in summer 2003.

As well as being funded and supported by Strategies for Living I am receiving a lot of emotional and practical support from East

Dunbartonshire Association of Mental Health and Revivisco Clubhouse (a place which focuses on people's abilities and skills rather than their ill-health). If anyone who either self-harms or works alongside those who self-harm, is interested in taking part in my research, or finding out any more information please get in touch. Any information I receive through this research project will be treated confidentially and protected through the Data Protection Act. ■

Nicola can be contacted either through Revivisco Clubhouse on Tel: 0141 775 3556 or on Tel: 07941 736454.

getting ethical approval -

Rachel Waters

Geraint Rees, one of the S4L supported researchers in Wales, and I recently attended an ethics committee meeting to gain permission to go ahead with Geraint's research project.

The project is looking at leave from hospital for patients detained under section 37/41 (these are patients who require Home Office permission for leave) and involves interviewing in-patients. This project is particularly innovative because Geraint is also an in-patient.

The meeting was held in the Local Authority offices - a huge building on an industrial estate. After a tense 15 minute wait we were invited into the boardroom by a man who referred to us as Mr Rees and Dr. Waters. We found this quite amusing as I'm not a doctor! However, it did draw attention to the fact that they are used to interviewing doctors and academics.

scary

On entering the room, I took a deep breath and tried very hard to stay calm - it was even more scary than I had imagined! The room was large and very

formal - the chairman seemed to be a very long way away from us. I tried to look confident and smile at all of the 10 or so committee members looking back at us. They all had titles in front of them and lots of them were doctors. There was also a nurse member, a pharmacy member, a Canon, and a Councillor.

The chairman gave a brief introduction (of which I can't remember a word having been overcome by adrenaline at the time!) and then asked us to give a brief oral description of our project. Geraint spoke for a few minutes to explain the project to the committee, and then I added some more information about user led research. The committee looked interested and asked a few general questions about the Strategies for Living project.

questions

We then moved on to the questions about the research. The first question was very complicated and jargonistic, about whether we intended to use grounded theory or were we testing a hypothesis? By the time I had worked out what the question actually

meant Geraint had started talking - explaining in plain English what we were planning to do.

There followed several more questions covering the nature of our sample, and the safe storage of data. We agreed to make a small change to our plans for keeping the transcripts safe, which seemed like a good idea.

structure

I felt the structure of the committee made it an intimidating experience for anyone putting forward a research proposal, including academics. However, it would be more difficult for people who are not academics or professionals because of the formality of the situation and the type of language used (Dr speak!). Geraint commented that it felt very much like a tribunal.

On the positive side, I was pleased that the committee took us seriously, had considered the relevant ethical issues, and did not patronise us at all. They were also very positive about user-led research, calling it 'innovative' and wishing us luck with the project. They have also said they would be interested in seeing the final results. ■

The first question was very complicated and jargonistic



Rachel Waters

S4L Research, Training and Support Worker for Wales

I was pleased that the committee took us seriously

spreading the word

Below are some of the recent successes we have had in raising the profile of work generated by and linked to **Strategies for Living**

- Vicky Nicholls, S4L UK Co-ordinator, gave a presentation on user led research at the Royal College of Psychiatry AGM in June.
- An article by Gill Malpas and Jonathan Weekes (ex-S4L researchers) on the benefits of drop-ins featured in the July edition of *Mental Health Today*.
- Ruth Sayers and Rosie Davies, S4L supported researchers from Bristol, presented their project to the National NIMHE (National Institute for Mental Health England) Conference and Meeting

on the theme of 'Experts by Experience' in Taunton in July. The project is examining guidance and support systems for people returning to work.

- Although not directly related to the work of S4L Toby Williamson has an article in September's edition of *Current Opinion in Psychiatry* entitled "Ethics of Assertive Outreach". It's

a review of recent articles and publications about assertive outreach and how they address the ethical issues that arise from trying to deliver this type of service to service users. It emphasises the importance of listening and responding positively to what service users say they want help or support with. ■

free publications for service users

We can now offer the following reports on user-led research projects free to service users and survivors:

- An investigation into auricular acupuncture.
- An investigation into drop-ins (exploring peer support in mental health)
- Research project into Mosque: exploring the benefits that Muslim men with severe mental health problems find from attending Mosque.
- Research project into user groups and empowerment
- An investigation into massage

For a report: send a self addressed A4 sized envelope (we will pay postage) indicating which report you require, to Strategies for Living at our London office address.

what's going on . . . at the mental health foundation

further information

Big Alternative Conference V Will be held on Thursday 3rd October in London. Key themes are self-help, innovative approaches to overcoming distress and new ways of thinking about 'recovery'. For more information contact Pavilion on Tel: 01273 623222.

Celebration of Christmas The Foundation's Celebration of Christmas takes place this year on Thursday 12th December at the Guildhall, City of London. Join us for a drinks reception followed by a carol concert in the Great Hall, featuring music from the celebrated London Chorus and readings from a host of celebrities. For ticket info please phone Louisa Livermore on 020 7802 0320.

recent publications

Today and Tomorrow

A report of the findings and lessons from the Growing Older with Learning Disabilities (GOLD) programme, a major project of the Foundation for People with Learning Disabilities. The report focuses on the themes of inclusion, health, older family carers, where people are living, dementia and Down's syndrome and terminal illness.

Updates: Research & Policy Briefings Vol 4

Yearly subscription rate: £99 for statutory services, £55 for voluntary agencies, £25 for unwaged service users and survivors

This subscription based monthly service is designed to keep everyone with an interest in health and social care up to date with the key messages arising from our work. Topics to be covered in volume four include dementia, advance statements and spirituality.

To order any publication please call the Publications Department on **020 7802 0300**

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