Where you stand affects your point of view. Emancipatory approaches to mental health research.

Notes from SPN Study Day 12 June 2003

SPN paper 4
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SPN Paper 4: “Where you stand affects your point of view”.
1 Foreword – Introduction to the Study Day  
– Jeanette Copperman, City University

There has been a growing interest in the politics and context of research—how and why it is carried out, and for whose benefit. We called this study day 'Emancipatory Research' to acknowledge the wider social and political contexts within which mental health research exists, and to suggest something which is evolving. We wanted to bring together a number of presenters with a range of approaches who are all trying to redress the imbalance of power between the researcher and the researched. We also wanted to make it an opportunity to think about different ways of finding things out and of using research. Traditionally the medical model has dominated mental health research; in the study day we intended to open up discussion about the different social frameworks which exist, including user-led research. We also wanted to highlight collaborative approaches which can help us reclaim the idea that our own life experiences are central to how we carry out research and what we do with it.

Paulo Freire coined the term 'emancipatory' in Latin America. Working with poor communities, he wanted to ensure that those with less power had the tools to give shape to their experiences, and directly linked that desire to action to redress power imbalances.

'It is research which has an explicit concern with ending inequality and taking the side of oppressed and marginalised groups...Knowledge is not just about finding out about the world but about changing it'  
(Humphries et al, 2000: p.4.)

Bringing with them a wide range of experience, presenters included users/survivors, user/survivor researchers, other researchers, practitioners, academics, trainers, people working in self-help groups, and activists. We wanted to ensure that the perspectives of groups who are often marginalised and excluded were included. The group least well represented on the day were frontline social-care practitioners.

For some time dissatisfaction with traditional research has been acute in the field of mental health, where the traditional biomedical approaches of psychiatry as 'the only way of knowing' have attracted increasing criticism. The growth of the user/survivor movement, work in the developing world, the women's movement, and adverse criticism of the Eurocentric basis of psychiatry—amongst other factors—have fuelled this. Presenters outlined ways in which users/survivors have often found their own lived experience missing from psychiatry's accounts, and user/survivor priorities not reflected in research funding. User-led approaches to carrying out research were presented and discussed.

Too often, prejudices against women, against Black and ethnic minority groups, and against gay men and lesbians and others have masqueraded as research. Many, including doctors, have also become uneasy at the disproportionate influence that the pharmaceutical companies exert (Abbasi and Smith 2003). We
wanted to bring together people who have been involved in thinking about these areas: doing research, contributing to it, and using it from a different point of view. In the intensely competitive world of funding applications, researchers can feel under pressure to do research which sticks to 'safe' topics, which can be funded more easily, and which is not critical of the status quo. This can make it hard to talk about the context within which research is located, and to share any misgivings. What happens if it challenges the status quo? We hoped that we would be able to speak about some of these things on this day.

Shape of the day
The day brought together various people, all of whom have been active in an aspect of research which in some way is based on the lived experience of service users, or of groups who have been marginalised or oppressed. In the morning there were conference presentations. Each conference presenter was asked to give a short presentation and talk about key aspects of his or her work. The conference then divided into smaller workshops. The workshops looked at participants' own experience of, and views on, being involved in research; and were asked to identify some research issues which SPN might want to see prioritised in future. These are included in the papers. In the afternoon there were more conference presentations and three themed workshops. Some of these—such as the 'Working Together' self-management programme developed by the Manic Depression Fellowship—explored links between research and practice. The day was not intended to reach any overall conclusions, but rather to offer an opportunity for participants to explore different aspects of 'emancipatory research' and make connections. Whilst some presentations—such as Peter Ferns’s overview of psychiatry’s history of oppressive research around race and culture—were critiques, others—such as Frank Keating's presentation on 'Circles of Fear'—described current research.

A strong theme during the day was the way in which user/survivors and activists have been developing different approaches to research—approaches which have at their core the lived experience of people going through mental distress, and which are sensitive to those experiences. Presenters from the Mental Health Foundation, Suresearch, the Sainsbury Centre for Mental Health, and the user-led research unit within the Institute of Psychiatry discussed work they have been doing for some time to develop research methods which are user-led. Others have been working to establish a knowledge base around the social—as well as the biomedical—factors which contribute to mental distress; or to focus on areas of experience which have been pathologised or marginalised. The papers which follow are notes that the individual presenters have made available, and a summary of themes from the morning workshops.

References:
2 A Brief History of Oppressive Psychiatric Research
(Race & Culture)
– Peter Ferns, Ferns Associates

Introduction
Research in psychiatry has been a rather long and winding road with some surprising twists and turns. The descriptions, analyses, and assumed causes of mental distress—as well as responses to it—have varied over time. However, there are some consistent patterns discernible, and a few valuable lessons to be learned from the past. People with inquiring minds will always investigate this issue, but it is to be hoped that they will gain some wisdom in their pursuit of understanding and knowledge by looking back at the mistakes of the past. Knowledge usually comes at a price, and that price is not always paid by the people who incurred the ‘debt’

In this paper I shall focus on a few examples around race and culture issues, but similar examples can be found in relation to age, gender, sexuality, and physical disability. The examples here range through justifications for slavery, debates about intelligence, eugenics, cross-cultural studies, and genetics. Finally, some of the abuses of research methodology will be highlighted.

Early History

“There are some remedies worse than the disease!”
(Publius Syrus, First Century BC)

‘The Cure of Folly’ by Hieronymus Bosch (1475)

“In this painting an old man is being operated on by a quack-surgeon who wears on his head “the funnel of wisdom.” The nun observing the operation is making the same absurd use of a medical textbook - which she balances on her head. To the left of the quack's head stands the gallows, as a sign of the wickedness of the world. More than a critique of surgical charlatans, the painting alludes to what Bosch perceived as the futility of psycho-surgery.”

From http://www.cinemaniastigma.com
‘Extracting the Stone of Madness’ by Pieter Brueghel (1557)

“In the 16th century it was widely believed that a stone in the brain was the cause of madness (hence the old cliché "rocks in the head"). A quack surgeon, toward the end of his "operation" would exhibit a stone supposedly removed from the patient’s skull. This 1557 engraving by Dutch painter Pieter Brueghel the Elder, satirises the psycho-surgical quackery of his day.”

From http://www.cinemaniastigma.com

A Phrenology machine (1907)

This mechanical device was designed in 1907 to assist phrenologists in making accurate psychological diagnoses.

“Dr. Franz Josef Gall’s (1758-1828) classification of mental faculties is a precursor to the present-day Diagnostic and Statistical Manual of Mental Disorders (the DSM). Dr. Gall was the founder of a branch of psychiatry known as ‘Phrenology’, a term which was derived from the two Greek words for ‘mind’ and ‘discourse’. After an extensive study of the brain Dr. Gall came to the conclusion that its various regions were correlated to specific mental functions. He reported that the concentration of fibre clusters indicated the degree of development pertaining to a particular mental faculty and that the outer conformation of the skull could be measured to make specific diagnoses.”

From http://www.cinemaniastigma.com

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‘Freeing the Patients’ (1792)

“In 1792, Dr. Philippe Pinel, a Paris physician, introduced the era of "Moral Treatment." Moral Treatment consisted of a proper diet, dignified work, kindness and respect. No restraints or punishments were used. The newspapers of the day were quick to point out the common basis between the French Revolution and the removal of restraints from "the mentally-ill." This form of treatment increased discharge rates to levels that, until then, had never been attained. By the following century, however, as the advocates of forced treatment introduced their "scientific advances" such forms of treatment slowly vanished and the level of discharge rates once again plummeted.”

From http://www.cinemaniastigma.com
Transition Years

Dr. Black’s list – Causes of ‘mental illness’ (1810)

<table>
<thead>
<tr>
<th>Causes, both Moral and Physical, ascertained in 249 cases.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Moral</strong></td>
</tr>
<tr>
<td>Domestic Grief, Affliction, and Disappointment ............</td>
</tr>
<tr>
<td>Unfaithfulness, Unkindness, or Intemperance of Wife ......</td>
</tr>
<tr>
<td>Loss of Situation and Dread of Poverty ....................</td>
</tr>
<tr>
<td>Want of Employment, and sufferings therefrom .............</td>
</tr>
<tr>
<td>Reverse of Fortune, Loss of Property, &amp;c. .................</td>
</tr>
<tr>
<td>Loss of Wife or Children ...... 3</td>
</tr>
</tbody>
</table>
| Disappointed Affection ...... 3                        | Disease of Brain ................................
| Unhappiness at Home ...... 1                           | Delirium Tremens ............................... |
| Erroneous Views in Religion ........................... 3 | Fever—Typhus .................................... |
| Sudden Shocks, Fright, &c. ........................ 29 | Yellow ...........................................
| Jealousy .............................................. 3 | Erysipelas .......................................
| Pride .................................................. 3 | Small-pox ....................................... |
| Non-success in Business ................................ 1 | Epilepsy .......................................... 14 |
| Responsibility and over-anxiety ........................... 1 | Paralysis ........................................ 6 |
| Sudden Loss of Several Cows ................................ 1 | Chorea .......................................... 2 |
| Regret for a Theft .................................... 1 | Injury to Retina ................................ 1 |
| Suicide of a Brother .................................... 1 | Disease of Lungs ................................ 3 |
| Over-excitement at the Great Exhibition .................. 1 | Liver .............................................. 1 |
| Hereditary Predisposition assigned .......................... 20 | Old Age .......................................... 4 |
|                                                      | Congenital Deficiency .......................... 16 |

89  57  1  5  3  6  14  2  1  4  14  6  2  1  1 |

Dr. Black’s list is an important document in the history of research in psychiatry because it represents one of the clearest departures from previous explanations of ‘madness’, as well as being the end of an era in non-scientific approaches to ‘madness’. For centuries ‘madness’ had been assumed to have supernatural causes such as ‘possession’ by evil spirits, or demonic forces, or vengeful gods.

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The list cites more social causes of ‘madness’ for the first time but it is still not very scientific, relying as it does on visible causes mixed with psychological and moral factors. ‘Madness’ is still seen as the failure of reason to control passion—as in earlier times—but Black’s language about ‘passions’ would not be acceptable to his immediate successors. It would be only forty years later that J.C. Bucknill would write that insanity is purely a disease of the brain. Henry Maudsley stated, ‘Insanity is in fact a disorder of brain producing disorder of mind; or to define its nature in greater detail, it is a disorder of the supreme nerve-centres of the brain …’ Black’s everyday social terms soon gave way to new scientific/medical terms, and psychiatry came of age. Medical and physical explanations of ‘mental illness’ gained ascendancy over earlier supernatural and natural explanations.

Dr. Samuel Cartwright – Mental health of slaves (1851)

In 1851, Dr. Samuel A. Cartwright was a prominent Louisiana physician and one of the leading authorities of the time on the medical care of ‘Negroes’. Dr. Cartwright claimed to have discovered two mental diseases peculiar to Blacks. These were called Drapetomania and Dysaesthesia aethiopica.

The first term came from drapetes (‘a runaway slave’), and mania, meaning ‘mad’ or ‘crazy’. Cartwright claimed that this “disease” caused Blacks to have an uncontrollable urge to run away from their home (the plantation) and their "masters". Dysaesthesia aethiopica supposedly affected both mind and body. He described it as ‘ hebetude of the mind and obtuse sensibility of the body – a disease peculiar to Negroes called by overseers – Rascality.’ The diagnosable signs included disobedience, answering disrespectfully, refusing to work, and deliberate damage to equipment and tools. The "cure" was putting the person to some kind of hard labour—which apparently sent "vitalized blood to the brain to give liberty to the mind"—and, of course, whipping.

Samuel A. Cartwright (1851) ‘Report on the diseases and physical peculiarities of the Negro race’, New Orleans Medical & Surgical Journal (May), 691-715
Emancipation from slavery

Dr. T.O. Powell – Slaves are mentally healthier (1895)

Dr. Cartwright also stated: “The disease is the natural offspring of Negro liberty – the liberty to be idle, to wallow in filth, and to indulge in improper food and drinks.” This theme was later developed, and was ‘proved’ in 1895 by Dr. T. Powell, Superintendent of the Georgia Lunatic Asylum. He compared the records of censuses taken between 1860 and 1890, and showed that insanity among ‘Negroes’ had increased from one in 10,584 to one in 943. Dr. Powell believed that the stable, secure, and structured lives led by slaves served as a protection against ‘mental illnesses’. Dr. Powell stated: “Freedom, however, removed all hygienic restraints, and they were no longer obedient to the inexorable laws of health, plunging into all sort of excesses and vices, leading irregular lives, and having apparently little or no control over their appetites and passions.”

The eugenics movement sparked off a huge amount of brain research. The movement originated from a cousin of Charles Darwin called Francis Galton, who coined the term ‘eugenics’ in 1883. He perceived it as a moral philosophy: to improve the human race by encouraging the healthiest and most able people to have more children than other less-deserving folk. Among other things, the movement openly advocated the protection of the nation’s gene pool from ‘mental defectives’. 348: ‘Exhibit of work and educational campaign for juvenile mental defectives’ Date: 1906 American Philosophical Society, ERO, MSC77, Ser1, Box 35: Trait Files

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Eugenics - Comparing babies' heads for racial differences (1921)
The ultimate in pre-judgement—before you are born!
564: Difference between white and negro fetuses
Date: 1921

Professor Robert Bean –
Comparison of ‘Negro’ and white brains (a study in research bias) (1906)
Robert Bean completed his study of ‘Negro’ and White brains in 1906 and he concluded that Black people had better ‘lower intellectual faculties’ of smell, sight, handicrafts, body-sense, and melody; while White people had better ‘higher intellectual faculties’ of self-control, will-power, ethical and aesthetic senses, and reason. However, his methodology left something to be desired.

“Bean's hypothesis was the intellectual superiority of the white Anglo-American race. To this end, he painstakingly measured the dimensions of two parts of the brain—the splenium (the front part of the corpus callosum) and the genu (the back part)—in around 200 brains from both white and black cadavers. A high ratio
of splenium:genu was believed to indicate a prominent forebrain and, therefore, more advanced evolutionary development…”

Subsequently, his findings confirmed a substantially higher splenium:genu ratio in Whites. However, at a later date:

“One of Bean’s mentors, Franklin P Mall, re-analysed Bean’s specimens with one crucial difference in the methods. He made his measurements without prior knowledge of whether the brain he was examining was from a black or white person.”

Mall’s results demonstrated “…no difference whatsoever between blacks and whites in this highly dubious measure of intellectual worth.”

Bean, R. B. ‘Some racial peculiarities of the Negro brain’ American Journal of Anatomy 1906: 5: 353-432. Quoted in “The New Research” and the primary care practitioner’ (article one) in Research Methods In Primary Care. This article was originally published in the British Journal of General Practice and is reproduced in electronic form by kind permission of the editors. At Web site: http://www.ucl.ac.uk/openlearning/uebpp/b1tnr.htm
Criminal brains (1921)
Obsession with brains extended to criminality as well. After all, if you can recognise criminals from their faces and the shape of their heads, why not their brains?


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The ‘female brain’ (1930)
The study of the brain also explained why women were so romantic!

633: "Love in its anatomical connections"
Date: 1930
Source: Cold Spring Harbor
Micklos: The Science of Eugenics, pg. 116

Dr. Paul Popenoe—Race & Intelligence: Part 1 (1918)
Dr. Paul Popenoe published the findings of his study, entitled 'Intelligence and Race--a Review of the Results of the Army Intelligence Tests--The Negro in 1918'. Incredibly, he propagated the idea that the IQ of Blacks was determined by the amount of "White blood" they had. The more light-skinned the Black person was, the higher his IQ; and the blacker he was, the lower his IQ. Popenoe concluded, "...the Negroes' low mental estate is irremediable...The Negro is mentally, therefore eugenically, inferior to the white race. All treatment of the Negro...must take into account this fundamental fact.'

"Intelligence and Race--a Review of the Results of the Army Intelligence Tests--The Negro in 1918."
Quoted in 'Psychiatric Oppression of African-Americans' at Web site http://www.cchr.org/racism/pooaa1.htm

Carl Jung - Theory of ‘racial infection’ (1930)
Jung held some strange views about the influence of Black people on White people who lived near them—derived from his trip to America in 1909. He postulated that White people who live near Black people have the ‘inferior layers of their psyche’ excited by them. Admittedly, he modified his views somewhat after events in Germany in the 1940s.

"Due merely to proximity to members of another race, an "infection of the primitive" has occurred within the collective racial organism of the white Europeans who colonised the new world."
Americans not only look different than their old world forefathers, but laugh, walk, and talk like the "coloured" peoples among whom they live: "Thus the American presents a strange picture: a European with Negro behaviour and an Indian soul." According to Jung, "the inferior man has a tremendous pull because he fascinates the inferior layers of our psyche"; perhaps the most dramatic consequence of "going black" is "the American sex problem...a marked tendency to promiscuity."

("Mind and Earth" (1927) quoted in „Im Anfang war der Rhythmus" Rhythmic incubations in discourses of mind, body, and race from 1850-1944 by Michael Golston in Stanford Electronic Humanities Review, volume 5, Supplement: 'Cultural and Technological Incubations of Fascism', Updated December 17, 1996)

Egaz Moniz: Inventor of the 'lobotomy' (1949)

Egaz Moniz was one of the very few psychiatrists to win a Nobel Prize. In 1946, he won it for inventing the 'lobotomy' technique. Unfortunately he had been shot in the spine and paralysed by a less-than-satisfied customer in 1939; and—with what can only be described as a strange irony—he was beaten to death by another ex-patient in 1955.

Walter Freeman’s ‘Transorbital’ lobotomy (1936)

“Lobotomised patients make rather good citizens.” (Walter Freeman)

Walter Freeman believed that he got his best results with women, Black people, Jews and “those with simple occupations”.

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“In 1936, Walter Freeman, an American physician, with his colleague James Watts, performed his first lobotomy operation. He was so satisfied with the results that he went on to do many thousands more, and in fact began a propaganda campaign to promote its use. He is also famous for inventing what is called ice pick lobotomy. Impatient with the difficult surgical methods pioneered by Moniz, he found he could insert an ordinary ice pick above each eye of a patient with only local anaesthetic, drive it through the thin bone with a light tap of a mallet, swish the pick back and forth like a windshield wiper and … a formerly difficult patient is now passive.”

(Dr. C. George Boeree, A Brief History of the Lobotomy, 2001)

By the way, Freeman was not a qualified surgeon—but that minor detail did not stop his relentless quest to administer his revolutionary ‘treatment’. He completed at least 3,439 lobotomies, his last one having taken place in 1967. (The patient died when he ruptured a blood vessel.)

"It was a brilliant cure - but we've lost the patient!"

Following a series of shock treatments at the Mayo Clinic in 1960 and 1961, Ernest Hemingway stated: "It was a brilliant cure—but we've lost the patient!" One month after his final shock treatment and a few days after being released from the clinic, Hemingway committed suicide.

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Drs. Heath & Bailey – Psychosurgery experiments on Black people (1950)

“Psychiatric "treatment" of African Americans has included some of the most barbaric experiments ever carried out in the name of "scientific" research—and not very long ago. In the 1950s in New Orleans, black prisoners were used for psychosurgery experiments which involved electrodes being implanted into the brain. The experiments were conducted by psychiatrist Dr. Robert Heath from Tulane University and an Australian psychiatrist, Dr. Harry Bailey."


Have we left this oppressive legacy behind? I’m not so sure.

In 1958, Audrey Shuey, author of the book Psychology and Life, wrote that IQ test scores ‘inevitably point to the presence of native [genetic] differences between Negroes and whites…” And this proposition has been put forward even as recently as 1994, with Murray and Herrnstein's book, The Bell Curve, claiming that African Americans do worse than Whites in intelligence tests, are ‘genetically disabled’, and therefore cannot cope with the demands of contemporary American society.
"... well-known differences in performance on intelligence tests of American blacks and white[s], with whites as a group regularly scoring higher than blacks as a group at all social-class levels, were due to inherent and essentially unchangeable intellectual differences between the two races, rather than to the effects of poverty, discrimination, and similar remediable factors"

In 1969, A. Jensen declared a genetic linkage of IQ to race in his article, 'How much can we boost IQ and scholastic achievement?' *Harvard Educational Review*, 39, 1-123; and in his subsequent books, *Race, intelligence and education* and *A Model for Intelligence* (1971).

Hans Eysenck largely agreed with Jensen, and argued that IQ differences between Blacks and Whites are due to genetic differences. In 1971, Eysenck published ‘The IQ argument - Race, intelligence and education’— based largely on the discredited work of Sir Cyril Burt. Both pieces of work were used to attack efforts to provide better educational opportunities for African Americans in the USA at that time. In ‘Inequality of Man’ (1973), Eysenck also made a connection between people's own mental abilities and genes, and social problems.

Pryce and Saifullah Khan—Problem cultures (1979)
Around the 1970s, we started to see the emergence of a new strand of racism in psychiatric research in which ‘brain inferiority’ gave way to ‘cultural inferiority’. For example, according to research done by Pryce, African Caribbean families in Britain were seen as having suffered ‘cultural stripping’ during slavery, leaving them ‘weak and unstable’ with a lack of paternal responsibility towards children. This view was likely to be further compounded by sexist stereotyping, largely due to African Caribbean families having women as their heads. On the other hand, according to Saifullah Khan, Asian families are too hierarchical, which leads to ‘stress-ridden relationships’—with Asian women being isolated because of their traditional views and customs. The lack of take-up of statutory services by Asian people is attributed to their lack of skills in Western lifestyles. In short, African Caribbean families are too chaotic and fragmented; and Asian families are too hierarchical and ‘enmeshed’.

Saifullah Khan, V. *Minority families in Britain: support and stress* (Macmillan, 1979)

Bebbington et al. – ‘Cheery Denial’ (1981)
Bebbington and his colleagues conducted a study to compare the incidence of ‘mental disorder’ in a Black group (African Caribbean) with that in White groups (Irish and English) in Camberwell, London.

"The differences in the pattern of disorder between the West Indians and Irish immigrants and the British-born in Camberwell seem to be real ones... In interviewing British West Indians in the community we were left with a distinct and
persistent clinical impression that they respond to adversity with cheery denial. We speculate that it might be possible to explain the apparent proneness of West Indians to major psychiatric disorder and their relative immunity to minor disorder in terms of this cultural characteristic—the Irish citizens of Camberwell seemed much more readily aware when things were going badly.”

Quoted in S. Fernando, Race and Culture in Psychiatry (London: Croom Helm; reprinted London: Routledge, 1989)

Fernando comments: ‘The researchers were explaining a lower incidence of depression and anxiety among black people by postulating a (pathological) “cheery denial”.


J. Philippe Rushton in "Race, Evolution and Behavior: a Life History Perspective " has argued that support for biological influences on character can be derived from racial differences in anatomy; and he has concluded that groups' differences in 'social organisation' versus 'reproductive effort' reflect long-running differences in evolutionary strategies. For example, in 'The Faster Race' Rushton explained that Asian and white infants are born with bigger heads than black infants. Hence Asian and white women have a bigger pelvic girdle than do black women. A smaller pelvis, Rushton claimed, is better suited to running. Asians and whites are brainier, blacks more athletic."

('The Faster Race' was a TV programme screened by BBC2 as part of its Black Britain Olympics Special in September 2000.)

In an article in The New Statesman, Kenan Malik states, ‘American journalist Jon Entine dismisses the environmentalist theory of black athletic prowess as “political correctness”. Entine's book, Taboo: Why Black Athletes Dominate Sports and Why We're Afraid to Talk About It, was published in America earlier this year to great controversy. The liberal consensus, Entine argues, has served only to disguise the truth about the black domination of sport—which is that blacks are built to run and jump.’

Malik goes on to state that ‘the real problem with the “blacks are born to run” thesis is not that it is politically incorrect and hence should be ignored, but that it

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Jesse Owens at the 1936 Berlin Olympics
is factually incorrect and should be challenged. The most basic difficulty is the confusion of racial and population differences.’

Differences between people will always exist, but they do not necessarily have to be linked to so-called racial differences—whether in sport or IQ tests.

‘According to Entine, East Africans are naturally superior at endurance sports, West Africans at sprinting and jumping, and “whites fall somewhere in the middle”. But if East and West Africans are at either end of a genetic spectrum of athletic abilities, why consider them to be part of a single race, and one that is distinct from whites? Only because conventionally we use skin colour as the criterion of racial difference.’

Kenan Malik, ‘Why black will beat white at the Olympics’, New Statesman (18 September 2000)

Other Bases of Oppression
The focus in this paper has been on race, but points just as disturbing can be made about gender or sexuality. For instance, it was only in 1973 that American DSM de-classified being lesbian or gay as a ‘mental illness’. The WHO did not engage in this declassification until 1992; it still has ‘egodystonic homosexuality’ as a form of mental disorder to this day.

‘In 1980, in the third revision of DSM, a new term "egodystonic homosexuality" was included. It was made plain that this condition referred to those who were unhappy with their homosexuality and who wished to change to heterosexuality. In 1987, a revised edition of DSM III removed "egodystonic homosexuality". In its place, there was substituted a reference to a sexual disorder, not otherwise specified, which included conditions of "persistent and marked distress about one’s sexual orientation". This classification persisted in the fourth edition of DSM in 1994. Of course, as with so many things psychiatric and psychological, questions remain. Is the disturbance referred to something that is personal to the patient himself or herself? Is it something that is inflicted on the patient by a family, a church, a society or, worse still, by the law with its heavy-handed sanctions? Or is this a construct of psychiatry or [sic] psychology themselves, seeing in the patient a "disorder" which psychiatrists or psychologists conceive from the depths of their own attitudes as human variation that they cannot, or will not, accept?’


Problems in research methodology

• Poor definition of concepts and ideas.
  ~ Many issues and topics researched are very complex, and can involve a high degree of subjective definition. Social context and personal bias may exert undue influence on the process of definition.
• Oversimplification of the issues.
  ~ There is a tendency to reduce a complex concept or behaviour to a set of
  measurable variables that may not truly represent its complexity. The issue of
  causation often becomes crucial, and there can be a temptation to view events as
  having a single causation or to confuse cause and effect.

• Poor survey and statistical methods.
  ~ The quality of evidence may not be properly tested, or may not be looked at
  critically: and any subsequent conclusions will then be flawed. This is particularly
  problematic with written records, where the authors may not be available or may
  not be known.

• Numerical values = scientific validity
  ~ Numerical values attached to data tend to lend them some unwarranted validity.
  For instance, for a long time IQ scores were seen as accurate measurements of
  intelligence. This false assumption resulted in a huge number of wrong decisions
  being made about people with learning disabilities, as well as the discovery of
  cultural bias in most IQ tests of that time.

• Ethnocentricity
  ~ Where the world is viewed from the specific cultural perspective of an ethnic
  group, and where a test or other research instrument is developed and tested on
  people from a particular cultural background and then assumed to be valid for all
  cultural groups.

• Colour blind approach
  ~ Where skin colour and racial differences are ignored as possible variables and
  are generally regarded as being an insignificant factor in our society.

• Creating racial and cultural dichotomies
  ~ This approach involves researchers regarding people from different racial and
  cultural backgrounds as being entirely distinct groups with no overlapping
  characteristics. There are many more similarities than differences between any
  two cultural groups of people.

‘Another, equally important, aspect of the contextualisation of research is the
social and political context in which it takes place. As Gould points out, the men
and women who built the now discredited tradition of craniology were among the
most distinguished scientists of their generation. What stands out from their
published work, viewed with the lens of hindsight and from a different ideological
perspective, is the naïveté of their hypotheses, the unjustified leaps of faith that
connected their biased measurements of brain dimensions with the intelligence of
the individual (and, implicitly, with the deserved social standing of the racial
group), and the presentation of political and ideological prejudice as scientific
truth.’

Research methods in primary care (article one): "The New Research" and the
primary care practitioner'
Changing ideas about mental distress

The following diagram represents the changing ideas about people who experience mental distress—showing the progression through the ages from medieval times to the ‘brave new world’ of genetic engineering.

Conclusion

Our scientific methods and technology may be more sophisticated today, but the human element of scientific process will always be there. The benefit of hindsight enables us to look back at these misguided attempts to tackle mental distress with a mixture of horror and amusement at their absurdity. However, we should not become too smug or complacent about our own efforts. No matter how much we try to delude ourselves that we have discovered an absolute truth or

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SPN Paper 4: “Where you stand affects your point of view”.
irrefutable fact about the human brain and its workings, there seems to be another fascinating layer of discovery that emerges. One wonders how history will judge some of our attempts at ‘treatment’.

There are always social consequences of research about people: maybe researchers need to do more analysis of these consequences at an earlier stage, and build safeguards into the design of their studies. We do need researchers to ask difficult questions and undertake complex research, but we must never forget the social implications for people who are the subjects of human research—whether in genetics, health, personality, or behaviour. Investigators and searchers for knowledge who ignore issues of equality run a high risk of colluding with oppression and allowing their own unacknowledged prejudices and stereotypes to influence their actions in a powerful way. Knowledge may be gained and science may progress, but the most vulnerable and disadvantaged in society will pay the price for progress that benefits others. Isn’t that at the heart of oppression? Good science will always be conducted within a social context which is clearly defined and understood. Striving to improve our methodologies in order to promote equality and empower people with greater knowledge will not only improve the quality of our evidence, but it will also be the right thing to do.

3 Emancipatory research in mental health
– Jerry Tew, University of Central England

Values
Within the field of mental health, much of the existing research and evidence-based practice has been founded on scientific methodologies, principally the randomised controlled trial, whose value base tends to assume that:

SPN Paper 4: “Where you stand affects your point of view”.

1. people are passive objects that have things done to them by the technologies and practices of expert professionals;
2. it is better—in order for research to be rigorous—if people are ignorant of what is being done to them and why;
3. questions of meaning, categorisation, significance, etc, are to be determined by the researchers and not the researched;
4. constructs (such as diagnostic categories) and results can be generalised without regard to questions of culture, gender, or other dimensions of diversity; and
5. it is the individual—rather than his or her social / economic / political context—who is problematic and in need of change

This value base fits certain more traditional forms of medical and psychological practice, but is seriously out of step with the empowerment/recovery focus of the new models of mental health practice that are being championed by NIMHE, and the more creative approaches to what constitutes 'knowledge' that are being developed by SCIE.

SPN is committed to promoting a different value base for research which assumes that:
1. people are active participants or partners in their own recovery;
2. people are experts on their own experience;
3. the research agenda must be as much about promoting social change (attitudes, opportunities, and so on) as about individual recovery;
4. service users, carers, and practitioners who consent to be subjects of research must be fully informed about the purposes of the research and, if they wish to have them, must be given the findings of the research in a form that is accessible to them.

Emancipatory research in mental health – what does this mean?
The whole research enterprise needs to be values-based, and needs to be conducted on the basis of dialogue and partnerships, rather than being imposed by an élite.

**Purpose of research**
To produce evidence and theory (concepts and frameworks) that can enable users and carers to:
• have a greater awareness of their situation so that they can make informed decisions and choices;
• have more control over their lives in areas where this may have been taken from them;
• participate in areas of social, economic, and political life from which they may have been excluded;
and can enable communities and practitioners to:
• challenge stigma, injustice, social exclusion...

N.B. Knowledge is power—so we need to look at who will 'own' or have access to the fruits of research, and how such people will use this power.
Process of Research
Stakeholders to participate in:
• constructing the research agenda;
• vetting the ethics of research proposals;
• selecting appropriate methodologies;
• carrying out the research;
• negotiating questions of meaning, categorisation, significance, etc.;
• disseminating results, and implementing them in terms of changing policy, practice, and social attitudes

What do we need to research from a social perspective?
In which areas would it be helpful to have a systematic evidence base?

<table>
<thead>
<tr>
<th>AREAS FOR RESEARCH</th>
<th>WHAT HAS ALREADY BEEN DONE</th>
</tr>
</thead>
</table>
| What are the social causes of—or factors contributing to—distress and relapse? | • Correlation with factors of social discrimination or deprivation (Fryer, 1995; Pilgrim and Rogers, 1999; Fernando, 1995; Williams, 1999)  
• Correlation with abuse, trauma and loss (Ensink, 1992; Mullen et al., 1993; Williams and Watson, 1996; Brown et al., 1995)  
• Patterns of family communication—‘Expressed Emotion’ (Leff et al., 1983) |
| What promotes recovery? | • Correlation with state of economy / cultural settings (Warner, 1994; WHO, 1979)  
• Social relationships (Brier and Strauss, 1984)  
• Long term follow-up studies (Harding et al., 1987)  
• Survivor narratives (Coleman, 1999)  
• Survivor strategies (Mental Health Foundation, 2000) |
| What is the impact of current practices? | • Evaluation of service models  
• User-focused monitoring (Rose, 2001)  
• Some initial research on the impact of compulsion and giving people a diagnosis—e.g., personality disorder (Barnes et al., 2000; Castillo, 2003; Ferguson et al., 2003) |

References:


Ferguson, I., Barclay, A. and Stalker, K. (2003) ‘“It’s a difficult life to lead”. *Supporting people with personality disorder: service user and provider perspectives*’ (Stirling: University of Stirling, Dept of Applied Social Science)


Mental Health Foundation (2000) *Strategies for Living* (London: Mental Health Foundation)


4. User Focused Research (Slide presentation)
- Dr. Jan Wallcraft, Fellow for Experts by Experience – NIMHE and Senior Researcher - User Focused Research – SCMH

4.1 New paradigms in research (1)
Focus on issues of concern to oppressed and marginalised groups
Use naturalistic methods instead of laboratory methods
Aim for honesty about research objectives and the effects of research on participants
Aim to be respectful, non-exploitative and to give something back to communities

SPN Paper 4: “Where you stand affects your point of view”.
New paradigms in research (2)
Make a commitment to empowerment and justice
Often research ‘with’ instead of ‘on’ people
Adopt collaborative and/or action research approaches
Often share research skills with oppressed groups, e.g. by offering training.

4.2 User led research - how it came about
Knowledge is power - personal empowerment through research
Researchers have mental health problems too
Local user groups doing surveys
Voluntary sector organisations supporting user-led projects
Collaboration between academics and service users

4.3 Examples of user-led research
SCMH User focused monitoring
Users’ Voices
In Our Experience
MHF Strategies for Living
S4L main report
Healing Minds
Doing Research Ourselves project
Anglia Polytechnic University/Colchester Mind - Personality Disorder research
Service User Research Enterprise (SURE) at the Institute of Psychiatry
On Our Own Terms at SCMH

4.4 On Our Own Terms: a study of the service user/survivor movement in mental health.
Jan Wallcraft with Jim Read and Angela Sweeney,
Sainsbury Centre for Mental Health 2003

4.4.1 Key objectives
To find out the extent and scope of the service user/survivor movement in England, and make this knowledge available to user groups and to decision-makers and practitioners
To research the current state of play in user involvement and make recommendations for improving practice.

4.4.2 Methods
Project steering group of service users including a number of Black service users
Project staff and research team all service users
Mapping user movement and postal survey of 315 groups
In-depth study with 25 groups, 30 movement leaders, and observations of user involvement in 8 local planning teams.

4.4.3 Key Findings
Service user groups form an identifiable movement with common issues
The movement provides mutual support, combats stigma, aids recovery and inclusion.
User involvement is an important activity but is secondary to mutual support function.
Black people are currently marginalised in the movement and need their own networks.

4.4.4 Implications of the study
Naming the movement and feeding this back could raise awareness and help growth.
This is a 'warts and all' honest appraisal of the movement's faults as well as its successes - may help overcome racism and other problems.
Policy makers may find it easier to provide the right kinds of support for involvement.

4.4.5 Where to from here? Shifting the psychiatric discourse
Writing about the existence of a phenomenon is a way to make it more concrete (see Foucault’s ‘Archaeology’)
The discourse of psychopathology has had many millions of words and £££££ spent on research to ‘prove’ its existence.
We still have a long way to go!!!!!!!!!!

References (1)
Wallcraft, Read and Sweeney (2003) On Our Own Terms, SCMH
SCMH (2003) Mental Health Service User and Survivor Movement Policy Paper
References (2)
Rose et al (1998) In Our Experience, SCMH
Mental Health Foundation Mental Health Foundation (2000) Strategies for Living: A report of user-led research into people’s strategies for living with mental distress, London: MHF.

5 Women and Mental Health Research

SPN Paper 4: “Where you stand affects your point of view”.
My own interest in research on women’s mental health—and in the silences within research—began when I became involved with Southwark Women and Mental Health Forum in the 1980s. This was a coalition of women who worked in mental health services and women who used them. A rape that had happened in a local psychiatric hospital was reported to us. We called a meeting, and—with minimal publicity—a number of women from different hospitals in the South East travelled to tell us about their experiences. They themselves had either experienced serious harassment or abuse within mental health services or worked with women who had done so. For some women it was the first time they had been listened to and believed. Women who reported rape said that they were often disbelieved, particularly if the attacker had been a staff member. Some had been told that it was 'a feature of their illness': rarely were the police called; and on even fewer occasions did the matter get to court. Women workers said they were often marginalised when they raised the issue. Services were reluctant to acknowledge gender, and the unsafe service environment for many users went largely unrecognised.

At the time I was doing a master’s programme in social policy, and decided to make this my dissertation topic. On doing a review of the literature I found that, despite the large amount of psychiatric literature on women—there were about 30 studies on 'sexual acting-out' alone (a pejorative term only ever applied—as far as I could see—to women)—there was almost complete silence in the research literature on sexual exploitation or abuse within mental health settings. There was one study in the journal literature that had looked at sexual assaults within psychiatric settings. It was from the United States; it had been conducted in one hospital only; and it did not break down the results by gender. It did, however, show that the rape reported to us was not an isolated incident: 38% of the residents in the American study reported having been sexually assaulted while in hospital; and 27% reported having been assaulted by staff (Nilbert, 1989). Why was there such reluctance to research something that so clearly was an issue?

This presentation is going to look at some of the criticisms of traditional research in mental health in relation to women; the contradictions that women have faced; and how feminist activists have tried to reshape thinking, to put different kinds of research questions on the map, and to raise some current issues.

Is it possible to be psychologically healthy and a woman?
There is a long historical association between women and madness (Showalter, 1987). In the 1970s feminists asked, ‘As a woman, can you be psychologically healthy in a misogynist society?’ Phyllis Chesler, in her book *Women and Madness*, pointed up some of the inherent contradictions in how women were meant to behave:

'Most twentieth century women who are psychiatrically labelled, privately treated and publicly hospitalised are not mad...they may be deeply unhappy, self destructive, economically powerless, and sexually impotent—but as women they're supposed to be.'
(Chesler, P., 1972: p25)
At about the same time, researchers investigating how mental health workers saw sex-role stereotypes found them to be very much alive in the mental health system.

**Sex-role stereotypes and clinical judgements**

Forty-nine professionals, including psychologists, psychiatrists, and social workers—31 men and 18 women—were questioned about their views of what constituted a healthy man, a healthy woman, and a healthy adult. They said that:

- male attributes included being very independent, not at all emotional, not easily influenced by others, very active, not excitable in minor crises, competitive, knowledgeable about the ways of the world, able to make decisions easily, and others;
- female attributes included being not at all aggressive, very emotional, not able to hide emotions, easily influenced, illogical, home-orientated, and not knowledgeable about the ways of the world.

The findings showed that the characteristics of a healthy adult as described by the clinicians paralleled those for the healthy man; in other words, it was hard to be both a healthy woman and a healthy adult in the mental health workers’ eyes. The workers devalued stereotypically female characteristics, yet thought that women should exhibit them. (Broverman et al., 1970)

**Feminist research and finding feminist methods**

*‘Your methods are a servant of your politics’*

(Williams J, Personal communication, 2003)

Following on from the activism of the 70s and 80s, feminists became interested in finding a feminist approach to research. Researchers such as Ann Oakley and Helen Roberts asked: who owns women's bodies? This led to questions about the relationship between women and medicine and women and their bodies (Oakley, 1993).

There was a commitment to ‘hearing the voice of the oppressed’. They wanted to ensure that women set the research agenda, controlled the research process, and interpreted the data using methodologies that would allow women to speak for themselves and bring out things that had been hidden. They

- were critical of traditional research and research methods;
- had a commitment to wide dissemination of the data;
- wanted to explore the experiences of women;
- wanted to find a framework for understanding sex differences; and
- aimed to generate findings that would be beneficial to women.

**Adverse criticism of traditional psychiatric research**

Feminists also became interested in the causes of women’s mental distress and the role that mental health services played. A number of feminist groups in Britain
found different ways to look at women's experience: not through the psychiatric prism, but from women's own points of view. Women articulated their experience through organising around issues and bringing together women's experiences to give shape to them. They also began to acknowledge the differences between women's experiences which are based on class, race and ethnic origin, age, and other variables—for example, MIND's ‘Stress on Women’ Campaign (1992) and ‘Eve Fights Back’ (1994); 'Good Practices in Mental Health for Women' (1994); and the 'Women and Mental Health Forums' Issues 1-9 (1994 -2002).

Some of the criticisms made of traditional psychiatric research on women:

- Traditional research in mental health pathologised women's experiences and ignored gender in the delivery of mental health services;
- Lack of credibility given to women's stories; decontextualisation of women's lives;
- Inequality a cause of women's mental ill health—but often ignored;
- Women far more likely to have experienced sexual abuse, rape, and violence before their entry to mental health services—a cause of women's distress that has often been ignored or pathologised;
- Causes of distress often hidden;
- Women conceptualised as men: lack of support with childcare; lack of recognition of childcare issues within services (medication and breastfeeding; loss of children and what that means);
- Pejorative ways of talking about women;
- Services can be retraumatizing for women: lack of safety; forcible treatment; being held down for forcible injections and ‘specialing’ by men;
- Diversity amongst women: experience of black, Asian, and other ethnic minority women; lesbians; older women; women in custody. Need to recognise issues for different groups of women.

Starting from the experience of women who used mental health services, different priorities were identified - such as these from MIND’s 1992 ‘Stress on Women’ campaign:

- An end to sexual harassment and abuse in mental health settings;
- The right of women to choose female care managers or key workers;
- Childcare for people who use mental health services;
- Service provision monitored by gender, and action to end unfair treatment.

Women organising around mental health has continued, for example in ‘Women Speak Out’ (Resisters, 2002, Leeds). Research carried out from women's own perspectives has been one important element of this. A study carried out in Leeds by ‘Women Speak Out’ in which all the researcher-interviewers were themselves service users/survivors found that some issues remained similar for women. Fifty-five women were interviewed and four focus groups were held.
Almost three-quarters of the women in the study talked about experiencing domestic violence, sexual abuse, and/or sexual assault; and the majority linked their distress to those experiences. Many women emphasised the need for services to engage with the causes—not just the symptoms—of their distress.

They found it hard to get information, hard to get help in a crisis, and hard to find out things when they felt at their lowest.

Most women preferred support from female workers but experienced difficulties in getting this.

Many women valued support from other women who used services; South Asian women had a strong preference for speaking to someone from a similar culture.

The vast majority of women who self-harmed spoke about being blamed and being treated as ‘timewasters’ by a range of workers

(Women Speak Out’, 2002)

**Feminist research**

Feminist writers and researchers began to look at such questions as:

- What is it about women’s lives that makes women more prone to depression and anxiety?
- Why are women more likely to be treated with ECT?
- Why are working class women and Black women less likely to get access to talking treatments?
- What does a diagnosis of ‘borderline personality disorder’ mean? How effective is treatment?
- Are mental health services a safe place?
- How does the mental health system treat mothers?
- What are the differences between the ways in which women and men access services?
- What brings women into secure settings such as Ashworth and Broadmoor?
- Why do so many women have eating disorders?

Three examples of feminist research in mental health:

*Women and self injury – Bristol Crisis Centre for women*
A survey of 76 women: women’s own experience of, and understanding of, their self-injury; their experience of service-provision; their perspectives on what helps. (Arnold, L., 1995)

Redefining Gender Issues, redefining women’s services, WISH
Penny Stafford looked at all the case registers in the special hospitals; found out from them about the backgrounds of the women and men who were in high-security accommodation; and talked to the women who used services in special hospitals
(Stafford, P., 1999)

Institutional Abuse in mental health settings: survivor perspectives
The study highlights retraumatization of women within the mental health system—drawn from work with women survivors on violence within mental health services from both patients and staff, and implications for women.
(Copperman, J. and McNamara, J., 1999)

The impact of feminist research in mental health and current issues
Getting rape and sexual harassment within mental health services recognised for what they were proved to be a long journey from that meeting in the 80s. A national working group was set up. MIND, COHSE, the RCN, and others became involved with changing policy and practice. Hospital policies were devised, and it became clear that the whole ward environment for women needed to be considered.

National policy did change, and standards now exist for women-only sleeping areas and for a woman’s right to choose her practitioner’s gender. There is a DOH national policy on women and mental health—Women’s Mental Health: Into the Mainstream 2002—but safety and retraumatization within mental health services remain issues for many women. A recent consultation with 100 women showed that lack of safety in British mental health services was still a major concern, as was ‘specialising’ by male staff (Sainsbury Centre, 1998; Williams et al., 2001). Although researchers have been able to get small sums for qualitative research, to date no large-scale research bid has succeeded in getting money to do a funded national study of sexual abuse within mental health settings in Britain. This is despite repeated attempts by researchers since the late 80s to put in well-worked-up research proposals with organisations such as The Prevention of Professional Abuse Network (POPAN) and Women in Special Hospitals (WISH), to build up a robust research base about abuse in mental health settings (Williams, J., Personal communication, 2003).

Currently there is also difficulty in getting independent research funding for large-scale work on the social context of mental health and social factors contributing to mental ill-health (Bifulco, A., Personal communication, 2003). The Medical Research Council (MRC)—a large funder in this field—has made an overall reduction in the number of studies that it funds, and is focusing on gene research.

Since the mid-80s it has become more recognised that giving disempowered groups a voice requires the use of different approaches. Feminist researchers
and the user/survivor movement have helped to influence the use of qualitative methods. But there is still a strong bias in favour of quantitative methodologies—and studies with control groups—when it comes to funding. Research work is resource-intensive, and the reluctance to fund challenging work is de-motivating.

**Depression, anxiety, and borderline personality disorder**

Similar issues exist in the funding of research on depression, anxiety, and so-called ‘borderline personality disorder’. These conditions affect more women than men. In recent times depression has not received much independent research funding; nor has it received much attention since the Royal College of Psychiatry-led 'Defeat Depression' campaign in the 90s. Anxiety is still not recognised as a disorder. There has been no public campaign on anxiety; there is less public knowledge about it; and its meaning has been blurred by pharmaceutical companies who want to suggest that drugs can be used for either anxiety or depression. In our mothers’ generation, hardly any women got help with depression; the situation has improved, but still only approximately 50% of women with depression access services. Only a third of those women suffering from anxiety access services.

Work following up the teenage children of a cohort of depressed adult mothers (Bifulco, A., 1998) has had difficulty finding consistent ongoing research funding. There is a need for funding of intergenerational work on depression (Bifulco, A., Personal communication, 2003).

Women's mental health has not had a high priority when it comes to funding. For example, research funding for studies on parents and children and mental health has focused on children. Research on personality disorders has focused on antisocial personality disorder; issues of risk and violence have received support and funding from within the Home Office, but women have not been a priority for this research stream. There is a need to research what is happening to women who have been diagnosed as having borderline personality disorder.

Activism around issues that are of importance to women has expanded the research horizon, but in the current absence of a strong national women's movement it is also possible for issues of importance to women to be lost from the research agenda. Whether the evidence generated by research finds its way into policy-making is dependent on many factors. At present feminist organising is patchy at a national level, but the current strand of user/survivor involvement in research offers many opportunities. When MIND launched its ‘Stress on Women’ campaign in 1992, forty-two trusts responded to a questionnaire asking whether they had any women-only wards or groups. Of these, only three offered any provision, and two of the three did so only on an acute admissions ward. It is now DOH guidance that ‘every acute service should provide a self-contained women-only in-patient unit’ (DOH, 2002: p.60). We hope that the work begun in Southwark Women and Mental Health Forum has contributed to that change.

**Questions**

What role can SPN play in working with other organisations to gain funding, generate knowledge about what services actually work for women, and help generate a robust evidence base?
Inequality is a major cause of mental distress for women. How can we embed perspectives on women and inequality within the new health inequality research agenda on an ongoing basis?

Is there some research that we could do looking at the treatment of women who have been diagnosed with so-called "borderline personality disorder"?

Is there anything that SPN should be doing in relation to the DOH National 'Women and Mental Health' Strategy?

References


Bifulco, A. (2003) Personal communication


Department of Health (2002) Women’s Mental Health: Into the Mainstream -available free of charge from DOH on 08701 555455


Resisters (2002) Women Speak Out (Leeds: Resisters) -available from resisters@aol.com


Williams, J. (2003) Personal communication
6 Researching ‘Race’ and Mental Health: Breaking the Circles of Fear
- Frank Keating, Sainsbury Centre for Mental Health

Introduction
‘Race’ and ethnicity—as they relate to mental illness/health—have attracted growing interest in the literature over the last three decades. These constructs are shrouded in complexity and fraught with contradictions. Such topics evoke a variety of subjective emotional responses ranging from fear through denial to prejudice. Utilising these constructs in research, therefore, brings us to one of the most contentious spheres of knowledge-construction, as well as of policy- and service-development, in mental health.

This presentation will draw on insights gained from a two-year research study conducted under the auspices of the Sainsbury Centre for Mental Health (SCMH)\(^1\) to explore fear and its impact on the relationship between mental health services and African and Caribbean communities. This research was not truly participatory, because it did not involve the communities under study in conceptualising and planning the study. I prefer to use the term ‘collaborative research’, based on participatory research principles. The study certainly had an emancipatory focus.

The rationale for collaboration
Even though they may be self-evident, it is worth restating the issues. There is agreement that most of the research on ‘race’ and mental health has not benefited Black (B) and minority ethnic (ME) communities. Moreover, these communities have been excluded from setting the research agenda and identifying ‘research problems’. Their needs, concerns, and interests certainly do not drive the agenda; and it was felt that a different approach was needed to compensate for the shortcomings in research.

The process of collaboration/participation
The study adopted a co-operative-enquiry approach to explore a range of perspectives on the impediments to change and to developing solutions. This was based on the premise that users’, families’, and carers’ knowledge and understanding about their own situation are essential components within the field of mental health. More importantly, we believed that knowledge can be co-constructed and that participatory methods lend themselves to achieving this aim. The study embraced a developmental approach to ensure that all phases of the research process were interlinked—that is, each stage in the process informed subsequent stages. The primary sources of data collection were: (a) a national call for evidence; and (b) focus groups involving service users, families and carers, and professionals. Participation in carrying out the study was ensured in the following ways:

a) A steering committee comprising key stakeholders—including service users, families, and carers—oversaw the strategic development of the study;

\(^1\) The full report 'Breaking the Circles of Fear' can be obtained from the Publications Department, Sainsbury Centre for Mental Health, 134 Borough High Street, London SE1 1LB. Tel: 020 7827 8300

SPN Paper 4: “Where you stand affects your point of view”.
b) An advisory panel with a composition similar to that of the steering group commented on operational matters such as questionnaire design, data analysis, and production of the final report;

c) Interviewers (12) were recruited on the basis of their experience, expertise, and knowledge on issues of ‘race’ and mental health. We therefore recruited service users and carers to lead those focus groups;

d) Training of interviewers took place in four meetings over a six-week period to allow time to develop shared understandings, a shared language for carrying out the interviews, and a common understanding of the aims and objectives of the study; and

e) All the interviewers were involved in developing the data-collection instruments, collecting the data, and producing the final report. Owing to practical considerations, fewer interviewers were involved in the data-analysis process.

Advantages of collaboration
Firstly, I found that we were able to make the study more relevant to the lived experiences and needs of services users, families, and carers. Participants commented that they felt that this research was ‘taking their concerns seriously’ and that ‘they were listened to’. Professionals, surprisingly, reported that this was the first time they had been given the luxury of talking about their concerns in relation to this area of work in a safe and open environment. This for me is the most significant advantage of a participatory approach. Secondly, the quality of the research process, the data-collection instruments, the findings, and the recommendations were much improved—because they were appropriate to, and sensitive to, the concerns of the study sample. Thirdly, we were able to engender trust in, and receive support from, the communities—which was pertinent, given the negative experiences BME communities have had of research. Lastly, because of the full involvement of service users, families and carers, and other key stakeholders in the research process, there was a sense of community ownership of the study and of the research process.

Lessons learnt
Participatory methods require time, commitment, and particular attention to process. The research tasks often dominate; and process issues—for example, perceptions about the research—are often neglected. I learnt that it was necessary to monitor the process on an ongoing basis—not only to ensure that everyone involved was still working to the same agenda, but also to make adjustments based on feedback received. By allowing time for the process, I believe that we were able to achieve the intended objectives of the study. Power emerged as a significant theme during the entire process, and a continual analysis of power dynamics was needed to make sure that no one agenda dominated. It was important for service users and family-and-carer interviewers to be treated as equals in the process, and to be assured that the final report would reflect their views and contributions. In the focus groups, participants were asked to develop solutions for change and to devise strategies for breaking down the circles of fear. It was remarkable, if not entirely surprising, to observe that participants were not really producing solutions, but were continuing to revisit problems. On closer analysis and later reflection, I concluded that it is unfair to ask individuals who are in relatively powerless positions to comment on issues
requiring a high degree of power and influence to achieve change (a very important lesson for user-involvement).

In summary, I conclude that participatory methods can ensure that research has relevance to the lives and concerns of service users, families, and carers. Voice can be given to the concerns of marginalised groups. It is therefore important to have a continual analysis of the dynamics of power to ensure that professional research agendas do not dominate. Participatory methods hold promise for strengthening the evidence base about social perspectives, and should be afforded a status equal to that of other research paradigms.

7 The Service User Research Enterprise: Developing the User/Survivor Research Agenda
– Angela Sweeney, Institute of Psychiatry

"The expression and experience of 'user-led research' in the UK has over
User involvement is fast establishing itself as an integral aspect of mental health services research. It is a term that is used by commissioners, funders, researchers, and practitioners alike—often to indicate some kind of authenticity and value in the work being conducted. It is now a requirement of many funding bodies, an oft-quoted development [e.g. (2)]. There appears to be an assumption amongst many that increasing the level of user involvement and control in the research process is a positive thing. As Beresford highlights, any criticisms of user involvement tend either to be unspoken or to focus on methodologies rather than the act of involvement itself (3).

Various authors have taken steps towards classifying levels of involvement, often reminiscent of Arnstein’s ‘Ladder of Participation’ (4). A commonly cited model ranges from consultation through collaboration to control, with different levels of involvement commonly achieved at different points in the process (5). Indeed, collaborative research can itself take many forms, and as a consequence can be difficult to define clearly (6). One example of a collaborative venture is the Service User Research Enterprise (SURE) at the Institute of Psychiatry. SURE was established in response to a consultation exercise in May 2000, which identified local mental health service users’ priorities for research. It was found that full user involvement in the research process was considered the key area needing change, with issues of content following in importance. A group was then convened to discuss how to take these ideas forward, leading to the establishment of SURE. The first co-ordinator, Diana Rose, was appointed in March 2001 under the directorship of Professor Til Wykes; every member of staff—bar the Director—has lived experience of mental or emotional distress and/or using services.

The unit’s aims are:
(1) to involve local users in research, and to support them in influencing the local research agenda;
(2) to undertake national research projects pertinent to users’ priorities, and to recruit users/survivors to conduct that research where possible; and
(3) to disseminate material to as wide an audience as possible.

To deal with the last aim first: talks, presentations, articles, reports, and papers in a variety of contexts help raise the profile of user involvement in research.

Returning to the first aim, this is currently addressed in five main ways.
• Local users are involved in research projects in an inclusive, empowering, and participatory way.
• Networking with local groups through visits and communications—such as the SURE newsletter—is an important part of staying relevant to local needs.
• Open meetings give an opportunity for local users to find out about SURE and get more involved.
• Through the summer of 2002, a local group of users/survivors successfully completed in-house training in research skills.
• Finally, a group called the Consumer Research Advisory Group or CRAG has been established.
The CRAG consists of up to 12 local service users supported by two SURE workers; they meet once a month. Two user representatives from CRAG are supported to attend a further group which is responsible for managing the area’s research and development money. Research conducted by the Institute of Psychiatry is of international significance, and the CRAG has an influence in defining and implementing its research priorities. Local users’ views are actively sought on research in general and on specific research issues through networking and through holding user-only events. For example, a Christmas conference called ‘Straight from the Horse’s Mouth’ at the end of 2002 discussed local users’ priorities for research topics. CRAG appears to be the only group of its type in the UK; it has been described as ‘an excellent example of how service users may be integrated into the research process in a structured and equitable way’ (7). It is hoped that structured, supported representation by the local community will help ensure that participation is conducted meaningfully. SURE also advises local academics on how to involve users in the research process in a meaningful way.

The second of the aims outlined above is met through conducting nationally significant research. This includes a Review of Consumers’ Perspectives [on] ECT, which revealed the complexity of users’ views and which was considered by NICE in its appraisal of ECT. A Review of Service User Involvement in Change Management looked at the literature regarding the theory and evidence of mental health service-user and carer involvement in effecting change in health and social care services—specifically focussing on factors which impede or facilitate user involvement, as well as power differentials. Affiliated to SURE is a project on Young people, mental health, and primary care, which aims to investigate who young people think is the most appropriate source of help for emotional problems, and how appropriate they feel the help of GPs is. The research I am involved with is exploring Users’ and Carers’ Perspectives on Continuity of Care. The broad aims are to discover what experiences service users have had, and what perceptions they and their families have acquired, on continuity of care; and to use these findings as the bases of two questionnaires which will measure users’ and carers’ experiences from their own perspectives. The research aims to be participatory throughout, and to contribute to user/survivor knowledge of people’s experiences.

User involvement in research has developed a long way since the idea was first mooted almost a decade ago—as related by Diana Rose in her BMJ article (8). In this same article, Rose goes on to suggest that the time is ripe for epistemological questions to be addressed if we are to demonstrate that user research is both rigorous and valid. The acquisition of knowledge through an exploration of experience—often key to user-focused research—must be firmly established in the hierarchy of evidence if involvement is to be empowering and if it is to help build an emancipatory path.

References:


SPN Paper 4: “Where you stand affects your point of view”.
8 Advance Statements - Working Together to make it ‘Better next time’
– Phil Alsop, Manic Depression Fellowship, Cambridge

Project:

To develop a tool for service users, when well, to inform future treatment when unwell. It eventually became known as an Advance Statement or Advance Care Plan.

Starting point and local context:

- The ‘Working Together’ movement in Cambridge (See: http://www.working-together.org.uk)
- A Community Psychiatric Nurse (CPN) who could work ‘adult-to-adult’.
- A little knowledge of Advance Directives.

Milestones:

- I make a presentation on Advance Directives to a ‘Working Together’ lunch and it goes down a storm! With hindsight I feel it’s because a) there is a clear need; and b) there are advantages to all parties.
- My CPN, Suzie, takes up the baton and convenes a working group with service users and professionals.
- Various drafts are considered and viewed favourably.
- Somewhere along the line we decide the legal/adversarial route is a red herring. The keynotes are co-operation and mutual benefit.
- More presentations to ‘Working Together’ lunches take place, and the impetus and involvement grow.
- There are pauses for illness, maternity leave, change of Trust structure, reorganisation, and job changes.
- The idea emerges as a coloured folder with dividers and room for inserts, Care Plan, etc.
- A final version is launched to the Cambridgeshire and Peterborough Mental Health Partnership Trust. Still early days! No detailed feedback yet.

Values:

SPN Paper 4: “Where you stand affects your point of view”. 
Respecting each other's expertise
Actively looking for positive benefits for all parties—service users, carers, and professionals
Allowing others to add in their ingredients
Showing patience and persistence
Modelling the tool to the behaviour we want to happen
Using the language of stating a preference, not that of making a demand
Working in harmony with NHS procedures, rather than against them

Points to ponder:

- Formal and detailed vs. open-ended and unstructured
- Plain vs. fancy
- The value of 'champions'
- Consensual vs. adversarial

Where now?

- It's still 'work in progress'
- Review in a couple of months.
- Possible refinements
- ... and, we hope, some people for whom it's 'Better next time'

Phil Alsop
Mental Health Service User and Secretary of Cambridge Manic Depression Fellowship Self Help Group.
May 2003

Invitation: I make no apologies for the fact that the content above is cryptic and very abbreviated. I am very happy to discuss anything you don’t understand or anything you have an interest in. Call me. E-mail me. You are even allowed to talk to me!

Contact details:
Telephone: 0845 458 1295 (evenings and weekend preferred);
E-mail: phil@mdfcambridge.org.uk   Web site: http://mdfcambridge.org.uk
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SPN Paper 4: “Where you stand affects your point of view”.
9 Personality disorder: temperament or trauma?
– Heather Castillo

The setting for the study was an established advocacy service run by Colchester Mind. During the 1990s a growing number of disaffected people with the personality disorder diagnosis had sought advocacy support from the service in Colchester; however, assistance in finding solutions to their problems had been largely ineffective. Some had simply been denied mental health services; others had lost their children via child protection procedures; some had been sent to secure hospital; and some had ended up in prison. In July 1997 a Consultant in Public Health for North Essex Health Authority published an article in The Guardian called ‘Everyone’s life has a price’. His suggestion that money could be saved by denying hospital admission to those with personality disorder prompted a local service user to write from hospital:

‘I am a victim of childhood sexual and ritual abuse. I am not yet a survivor. I don’t see why I should be deprived of the care and expert counselling that I most definitely need. It was, after all, not me who carried out abuse on a minor. I am just trying to cope with the aftermath’.

By July 1999, the Home Office had issued policy proposals for managing dangerous people with severe personality disorder—suggesting removal to special units, even without a deterioration in their clinical state, if they were deemed potentially dangerous to the public (DoH, 1999). This seemed to cause fairly widespread fear amongst those with the diagnosis. The Advocacy Service began to hear from anxious service users who had at some time received the diagnosis, or who had at some time assaulted another, no matter how minor the offence. Despite assurances regarding the small number proposed for indeterminate detention and their historical dangerousness, many were not calmed. (‘This is doing time for no crime’; ‘It’s the thin end of the wedge.’) The impulse to form a local research group arose from a growing and shared sense of alienation amongst those who had attracted this label.

Our group of 18 service users, all of whom had received the ‘personality disorder’ diagnosis, met monthly throughout 1999. Our inquiries began with an examination of the history of this diagnosis, which—we were to discover—spans two hundred years, beginning in 1801 with a French psychiatrist, Pinel, who spoke of ‘mania without delirium’. Throughout the nineteenth century, the concept of this condition included terms such as ‘moral imbecility’, ‘degenerative deviation’ and ‘psychopathic inferiority’. Setting a diagnostic course for the future, Henry Maudsley wrote, in 1885:

‘It is not our business, and it is not in our power, to explain psychologically the origins and nature of these depraved instincts; it is sufficient to establish their existence as facts of observation’.

Today, following in a tradition of psychiatric observation which is concerned with surface manifestations, the American and European diagnostic manuals refer to enduring patterns of behaviour that deviate markedly from the expectations of the individual’s culture; and pervasive, inflexible deficits which are stable over time

SPN Paper 4: “Where you stand affects your point of view”.

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(DSM IV, 1994; ICD 10, 1992). This gives the service user little cause for hope. It is a category which does not have much scientific credibility, and it is a diagnosis which is often hidden from patients. This caused Lewis and Appleby (1988) to report, in their study entitled ‘…The patients psychiatrists dislike’, that such patients are widely held to be untreatable, and that professionals view such service users as long-term management problems. This prompted Lewis and Appleby to conclude that ‘personality disorder appears to be an enduring pejorative judgement rather than a clinical diagnosis’.

When service users are devalued, it is difficult for them to question the assumptions of the majority by themselves. The support of other people who share experiences and perceptions helps to set in motion collective action—which may challenge conventional wisdom (Brandon, 1995). A research partnership was, therefore, created whereby the study was managed by the Advocacy Service of Colchester Mind, and supervised and funded by the School of Community Health and Social Studies at Anglia Polytechnic University.

Although there are ten diagnostic sub-categories attributed to personality disorder, the two most commonly diagnosed are ‘borderline personality disorder’ and ‘dissocial/antisocial personality disorder’. This was reflected in our group, where all members had acquired either a ‘borderline’ or ‘dissocial’ diagnosis. Service users with borderline personality disorder are characterised as emotionally unstable, impulsive, and self-destructive; while those with dissocial personality disorder are described as having a callous unconcern for others, combined with deviant social behaviour and a potential for danger to their fellows. Therefore, a vital early group decision was whether members with a ‘borderline’ diagnosis would be amenable to, and would feel comfortable about, including those with a ‘dissocial’ diagnosis. This was an important ethical decision because it might be considered that ‘abused’ and ‘abuser’ would be drawn into unwilling association. Identifying common issues of stigma, discrimination, and early life events, the group found a consensus in favour of inclusion. In fact, esprit de corps came easily to this group. Why should this be? After all, some were considered to be such ‘difficult customers’. Solidarity against the world, perhaps? Our group had certain hallmarks. It was always the same room we met in. Warm. Next to the smoking room. With a bottomless supply of tea, coffee, and biscuits. Group cohesiveness deepened throughout the year— with much exploration of loss, early history, experiences within the psychiatric system, and common coping strategies. The group was always unstructured. It resisted structure and ambled its way through two hours on a Thursday afternoon. Yet much was discussed and much was achieved.

Nine group members began to produce stories in order to examine the relationship between life events and their disorder (Brown and Harris, 1989). Some agreed to keep journals; others, to write poetry or letters. Five members of the group expressed a wish to be trained as researchers in order to interview fifty other people with the diagnosis in the Colchester area. With the help of supervisors, the group set out to create an interview questionnaire. The study used a mixture of qualitative and quantitative methods. The questionnaire began qualitatively, with a semi-structured interview. The group wished service users to explore and share their experiences. They wanted to show what it really means...
to receive a diagnosis of personality disorder. They wished to know what the
diagnosis meant to the service users, how they had discovered they had this
diagnosis, how this had made them feel, what they considered to be their
problems and strengths, what if anything had helped, and how — in an ideal
world—services should be run. The remainder of the questionnaire was
quantitative, with a fixed format which included demographic and diagnostic
information, life experiences, symptoms, behaviours, and a rating table for types
of support and intervention.

In April 1999, a five-week training programme was launched by the Advocacy
Service Manager, with supervisors from Anglia Polytechnic University, involving a
co-operative-inquiry group of service users from Lifecraft in Cambridge. Training
included communication and interview skills, ethical issues, and good practice—
along with practical issues concerning timetabling, the environment, support, and
expenses. It was agreed that researchers would receive a payment of £30 for
each interview conducted, and respondents would receive £10 for their
participation.

It is important to understand that the researchers were not ‘survivors’ engaged in
a retrospective study, but rather ‘sufferers’ struggling for emotional equilibrium
while engaged in a research endeavour. Consequently, our study was fraught
with questions regarding who might relapse next, and ethical dilemmas regarding
the stressful nature of our inquiry. Five researchers would become four almost as
soon as the training programme had begun. Two more would be admitted to
hospital during the course of the study. All four researchers negotiated very great
personal difficulties during this time, yet all four continued to contribute to the
study again as soon as they were able. One said, ‘If I give up hope on this, then
there’s nothing left’. Other group members experienced their own individual
problems. They still came to join us each month. Some came from the hospital
wards. Some came even when ‘sectioned’. The commitment was breathtaking.

Once training and pilot work were completed, it was necessary to obtain ethical
permission to carry out our study. We were invited to attend a meeting of the
local Research Ethics Committee on a warm evening in May. One of the service-
user researchers accompanied the Advocacy Service Manager to the meeting.
Bearing the scars of years of self-harm, she paused at the entrance and asked,
‘Do you think I should cover my arms?’ On reflection, she did not feel she should
have to do so. She sat with some dignity and answered questions articulately
and with candour. However, we suspected that such a research proposal might
prove an uncomfortable proposition for any research ethics committee. Our
suspicions were confirmed, and it took over three months of negotiations before
permission for the study was granted. In the meantime we launched our research
on a self-selected basis involving members of the group only. During August,
ethical permission was received. By this time we had already completed fourteen
interviews.

After permission was obtained, we followed the guidance of the Ethics Committee
by contacting seven local consultant psychiatrists with details of our study, and
asking for suggested respondents. Although the psychiatrists were very co-
operative in other ways—they did not cause delays and they did not refuse

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access to any of their patients—they suggested very few respondents for the study: three in all. By late November we had completed forty interviews. Respondents had been accessed almost entirely by the networking activities of the advocacy service and the group. Only two had refused to be interviewed. Such a high response rate might be viewed as a testament to the level of support service users were willing to give to other service users involved in research. The voluntary sector rallied support in the last few weeks, helping us to access the remaining ten interviewees. Nineteen interviews were conducted in respondents’ homes; eighteen took place in hospital; nine were carried out at the Mind Social Centre or nearby voluntary centres; and four people responded by mail. (Two of these had moved out of the area recently, one was in an out-of-area secure unit, and the fourth was in prison.) By 20\textsuperscript{th} December, 1999, the last interview had been carried out. The sample of fifty was now complete.

Capturing the voice of the sample, the study yielded an abundance of service-user perspectives, and the completed research report was to include almost fifteen thousand client words. The study consisted of 50 people, 40% of whom were men and 60% of whom were women. Ages ranged from 18 to 74. The majority of interviewees, 86%, were aged between 25 and 54. Eighty-six per cent were single, divorced, or separated; and 66% were living alone. Eighty-eight per cent were on long-term sickness or other benefits. Just one was employed full-time. Fifty-eight per cent had a diagnosis of ‘borderline personality disorder’; for 28%, it was ‘disocial’; and for the remaining 14% the personality-disorder diagnosis was unspecified. An analysis of additional psychiatric diagnoses showed that 78% had a diagnosis of depression and 60% had one of anxiety. Eighty-six per cent of service users in this study described their difficulties in terms of depression or anxiety—or often combinations of both. So why should they have received a diagnosis of personality disorder? Four interviewees had recently received a re-diagnosis of bipolar or mood disorder. All four were articulate, and were not slow to express their grievances. It may be that they had originally received a diagnosis of personality disorder because they were perceived as troublemakers. However, a question existed: was there anything linking the remainder? The findings revealed a correlation in terms of early trauma and often-brutal life experiences. Eighty-eight per cent had suffered abuse—violent, sexual, and/or emotional—and for 80% this had been childhood abuse.

There exists extensive support for the concept of a complex post-traumatic syndrome in survivors of prolonged and repeated victimisation (Herman, 1992; Van der Kolk, 1996; Fonagy, 1997). Behaviour manifestations including self-mutilation, re-victimisation, victimising others, dissociative disorders, substance abuse, and eating disorders—employed as strategies aimed at regaining internal equilibrium—have been discovered in victims of early trauma. This suggests a tendency, in later life, to cope with thoughts and feelings through physical action. (‘Do it either to my body or to your body.’) Not being able to find themselves from within, individuals are forced to find a sense of self from the outside by treating themselves as objects or by getting others to react to them. The findings of our study concurred, in that 88% had engaged in self-harming activities such as cutting, overdosing, or self-starvation; 76% had engaged in alcohol or drug misuse; and 82% had attempted suicide.
Erving Goffman (1961) examined the ‘moral career’ of the service user in the context of identity. By this method, the process of development can be followed by studying moral experiences and personal adjustments. An ‘alteration of social fate’ began for our sample with the revelation that a diagnosis of personality disorder had been conferred. The reactions to this new-found knowledge included: 'anger', 'feeling insulted', 'blamed', 'depressed', 'anxious', 'daft', 'abnormal', 'numb', 'bewildered', 'helpless', 'shocked', and 'excluded'. Confirming that the diagnosis is stigmatising, service users described being treated as ‘services lepers’. Others said ‘you’re ignored’; that the label ‘arouses hostility’; that it was considered to have been ‘brought on oneself’; that ‘people seem to be scared of the diagnosis’; or ‘it’s saying “troublemaker”’. Many discovered indirectly that they had the diagnosis, from records, from reports, or at meetings. Others appear to have been told only after many years, and yet others were given the information by professionals only after they had asked. The sense of exclusion and hopelessness expressed by respondents on making this discovery gives some insight into the impact the information might have on an individual already labouring with the desperately hard task of living with the truth of an early abusive history (Castillo, Allen and Coxhead, 2001).

‘We already feel subhuman, threatened, and vulnerable, and now we are tarred with the brush of being bad as well as mad.’

Twenty per cent of the women in the study had been violent to others, as had 22% of the men. More than 75% of the women had received a ‘borderline’ diagnosis; and more then 75% of the men, a ‘dissocial’ diagnosis. None of the men with a ‘borderline’ diagnosis had been violent to others. Thirty-five per cent of the women with a ‘borderline’ diagnosis had engaged in violent acts, yet had retained the ‘borderline’ categorisation. Does this suggest that violence in men might attract a diagnosis of psychopathy more easily than in women? Does it highlight the greater likelihood of a prison disposal on the basis of gender? Certainly 26% of men in our study had experienced prison, compared with 12% of women. Fifty per cent of the men with a ‘dissocial’ diagnosis considered their strengths to be care and compassion. Rather than corroborating the stereotypical notion of the psychopath viewing fellow human beings as ‘empty vessels’, they characterised themselves as ‘Jekyll and Hyde’—an embodiment of both compassion and aggression. They highlighted the fact that aggression has a context, and that strengths may go unrecognised. Whether the categorisation is ‘borderline’ or ‘dissocial’, our study shows high incidences of early abuse, self-harm, and suicidality across categories. Women with a ‘dissocial’ diagnosis in our study all had a history of early emotional abuse, but none had a history of childhood violence; yet 67% had been violent to others. Of the men who had experienced early violent abuse, some went on to harm others while some engaged in self-harm. These findings suggest that violence does not necessarily beget violence; but that early, unresolved, and unassimilated trauma can result in the perpetration of harm. This may be directed inward as self-harm or outward as harm to others. This questions the validity of the diagnosis of ‘personality disorder’ and the sub-categories within it.
In this study, service users have proclaimed that ‘when you are abused as a child, your life is murdered’. Self-states had resulted in suicide attempts of such lethality that survival seemed miraculous. One group member threw herself down a sheer 40-foot cliff face. ‘It’s amazing how many people try to kill themselves and fail. I feel that even God does not want me.’ Anger had become dammed up behind a narrow response function. Words had been cut into flesh. Etched in red against the background of a beautiful young arm was the word ‘hate’. Where early life had been sexually or violently abusive—or had simply included an unloving, profoundly humiliating, and devastating non-response from caregivers—the blunt limitations of their experience had left some stripped of control and disempowered beyond belief.

An analysis of what helped most revealed that service users seem to be saying: understanding and acceptance will get professionals halfway there. The most frequently reported, and most unpopular, professional response in this study was telling patients that they were ‘attention-seeking’. To say that someone is attention-seeking is to imply that the person is not worthy of attention. It is dismissive. Behaviour can be a form of communication, and the ways in which the system responds to this behaviour may also be dysfunctional. Professionals could try to see behaviours such as self-harm, continual neediness, and suicide attempts rather as ‘attachment-seeking’, which might be better understood in terms of attachment theory and separation anxiety (Bowlby, 1988). The findings include service-user observations about a wide variety of therapeutic interventions. Cognitive analytic therapy (Ryle, 1997) received the highest therapy rating in our study. ‘I’ve seen him (the therapist) for over a year. He’s done more than the whole services put together.’

As far as we are aware, this is the first study of its kind where service users have become equal partners specifically engaged in researching a clinical diagnosis (Ramon, Castillo and Morant, 2001). Employing an emancipatory research approach, the service users diagnosed with personality disorder have replaced ‘the view from above’ with ‘the view from below’ (Freire, 1970). Here the research tools have been given to the people, and with them they have presented a new construct for consideration—a construct which points overwhelmingly to the need for a redefinition of this diagnosis into a category which more clearly suggests aetiology and which offers a better understanding of this human condition.

‘From the perspective of those of us involved in this study, the experience has indeed been emancipating. It has given us a voice and an opportunity to put forward our side of the story and tell you how it really feels. This is an opportunity we have made the most of. We are proud to say that eight articles about our research have been published in national journals, and half of those were co-authored by service users involved in our study. We have presented the results of the research at over twenty conferences. Some of these were high profile national conferences where, often with shaky legs and trembling voices, we have spoken our truth on platforms shared with some of the most famous names in the field. For once in our traumatic lives we have felt valued and respected. Slowly we are seeing a shift in the views of some professionals who no longer see personality disorders as untreatable and are helping to develop excellent long-term programmes which are increasingly proving that this is not the case.’
As for the group, we re-formed in February 2001. We still meet monthly, and we also publish a news-sheet which has a national circulation. Some of us have moved on, got married, managed to get our children back, started academic courses, even begun part-time work—but others still struggle badly. And so the work continues. In 2002, our group became involved with the Department of Health in relation to the new National Guidance (DoH, 2003); and in January of last year, our study was published as a book (Castillo 2003).

References:

Department of Health (2003) Personality Disorder No Longer a Diagnosis of Exclusion, (National Institute for Mental Health in England)
ICD 10 (1992) Classification of Mental and Behavioural Disorders (Geneva: World Health Organization)
Maudsley, H. (1885) Responsibility in Mental Disease (London: Kegan Paul)
10 Gaining Access to and Working with Self-Help Groups in Mental Health
- Eleni Hatzidimitriadou, Tizard Centre, University of Kent

Introduction
In the last few decades there has been a remarkable expansion in group activities devoted to self- and mutual help, mainly in Western countries; this is an important political development which challenges conventional welfare concepts and traditions of charity and voluntarism. The popularity and rapid growth of such groups in the mental health field has been attributed to a variety of social and organisational reasons, namely: de-institutionalisation and the shift to community care; increasing dissatisfaction of users and carers with services; the growing user/survivor movement; and an emphasis on self-empowerment.

Self-help/mutual-aid groups share common attributes: they are formed and controlled by peers with a common problem or condition; they have voluntary character; and, at least in North America, they have little or no connection with professionals. A great difficulty in defining self-help is its evolving character, expressed in various forms; hence, it proves challenging to describe self-/mutual-help activities in a comprehensive way. Nonetheless, in all forms of self-/mutual help, there is an ethos, which is defined as ‘a constellation of norms and sentiments, a series of themes that underlie behavior’. These themes are: the ‘anti-big’, anti-bureaucratic, non-hierarchical character of self-help; the reaffirmation of basic core traditions of community such as neighbourhood, spiritual values, and self-reliance; the empowerment process and the democratisation of everyday life in the sense of demystification of mental and physical illness, ‘anti-elitism’, and ‘anti-expertism’.

Recognising their socio-political singularity, Wann (1995) emphasises that ‘self help and mutual aid stress personal responsibility and interdependence, as well as direct, local action. They present an ethos which is empowering and enabling rather than protective, prescriptive or philanthropic’ (p.1). These characteristics of self-help (mutuality, egalitarianism, and empowerment) constitute a major challenge to the power of professional groups; and—given the fact that statutory services in many countries face a plethora of important financial and organisational problems—this is especially true in the field of mental health.

There is an ongoing debate about the nature and role of these groups, especially in the mental health area—in particular, about whether they are another form of treatment or part of a new social movement. The main body of research in the area is merely concerned with group helping mechanisms and individual benefits from group participation. Among the most frequently mentioned outcomes are: increased social support and networks, empathy, sense of belonging, personal empowerment, information and education, and new coping strategies. In order to explore possible variations in, and outcomes from, these groups, it is important to depart from the narrow psychotherapeutic perspective and recognise their

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2 Katz & Bender, 1976; Kurtz, 1997
3 Riessman & Carroll, 1995, p.1
4 Chesler, 1991a; Katz, 1981; Riessman & Bay, 1992

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potential to assist mental health service users in regaining control over their lives and coping actively with their problems. To date, little effort has been made to explore more systematically fundamental factors of the self-help phenomenon such as the socio-political character of groups, the specific help-giving activities occurring during meetings, and the components of members’ personal empowerment as a result of group participation.

In the light of these observations and the limitations of existing research, the aim of my study was to explore the relationship between the political ideology of self-help/mutual-aid groups and the specific psychosocial characteristics of their members. These characteristics were studied at two levels: the individual level, by looking at mental well-being, personal empowerment, social networks, and perceived support of group members; and the group level, by examining group identification and helping processes occurring during meetings. The main research question of the study was whether self-help/mutual-aid groups differ according to their political ideology and focus of change in terms of empowerment and group helping processes.

Methodological Considerations
Systematic research on self-help/mutual-aid interventions has unique and complex elements; and, accordingly, is difficult to conceive and implement with existing tools and traditional methods. There is surprisingly little substantial research on self-help groups, despite years of clinical and policy interest. Goldklang (1991) notes that research on naturally occurring self-help groups is at a rudimentary stage and, as such, presents a picture similar to that of psychotherapy-outcome research in the 1950s. Global questions instead of specific ones are being asked about effectiveness, and the nature of self-help interventions is ill-defined. Further, he emphasises a distinctive feature of research in self-help:

‘researchers are guests in naturally occurring self-help groups and not hosts … [they] need to be responsive to the needs of self-help groups … [so] the outcomes measured must include variables of interest to the participants.’ (p. 791)

In their critique of existing self-help research, Tebes and Kraemer (1991) discuss the inherent complexity that professionals and researchers face if trying to study mutual support quantitatively—that is, using traditional research methods such as experimental designs, comparisons of self-help with control groups, and pre-/post-intervention measurements. They identify three critical issues which contribute to this complexity and which impede ‘scientific’ knowledge of mutual-support phenomena:

• the lack of researcher control over the intervention, which is due to the peer-led character of self-help groups and the peripheral role of professionals in them;

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6 Hatzidimitriadou, 1999, 2002
7 Goldklang, 1991; Tebes & Kraemer, 1991; Humphreys & Rappaport, 1994

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the “perspectival discrepancy” ; that is, ‘the difference in perspective between the self-helper and the researcher about the nature of the group process and what constitutes outcome’ (p. 742); and

the lack of consensus among investigators about how to conduct scientific research on mutual support.

The authors argue that, in order to overcome these difficulties, it is important to re-examine the scientific methods used in the study of social phenomena such as self-help/mutual-aid groups. Although they acknowledge the usefulness of experimental and quasi-experimental designs for the understanding of human and social phenomena, they criticise such designs as currently implemented, considering that they fail to capture the richness and complexity of these phenomena. Tebes and Kraemer (1991) point out that in order to study self-help/mutual-aid interventions we need an alternative approach—that is, integration of qualitative and quantitative methods. The incorporation of qualitative knowing into quantitative designs allows investigators to monitor closely the ‘local conditions’ (the specific and unique characteristics of the local setting which provide the context for a study), thus permitting them to address the difficulties described previously. Qualitative knowing employs methods that share a number of characteristics: naturalistic inquiry, inductive analysis, fieldwork, and adoption of a holistic/ecological viewpoint. Some of the qualitative approaches that Tebes and Kraemer (1991) suggest as being appropriate to research on mutual support are: the case study, participant observation, process-evaluation, and adversary hearing.

Chesler (1991b), reinforcing the view about the appropriateness of alternative methods for the research of self-help groups, applied the model of participatory action research as an alternative research paradigm. He argued that

The alternative approach of participatory action research (PAR) is quite congenial with the highly participatory and experiential culture and goals of self-help … [because] it employs technologies of data collection and analysis that are congruent with the reliance on local wisdom and lay leadership that runs through the self-help movement … [and] the ways in which participatory action research generally utilizes research findings is more consistent with the organizational structures and action needs, as well as empowerment potentialities, of self-help groups. (p.758)

Central features of this alternative research paradigm are that the researcher is committed to personal activism, and that there is a high degree of co-operation and involvement between researcher and participants, with constant feedback processes. Most important, the goal of participatory action research is the implementation of the findings in order to address social issues

There are a number of advantages for the self-help researcher if s/he adopts this alternative type of research. First of all, its flexibility may help the researcher to adequately tap, or be relevant to, the real-life heterogeneity of self-help groups. In addition, with collaboration and active participation, researchers may improve their access to the groups and may have first-hand experience of them.

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8 Chesler, 1991b; Rogers & Palmer-Erbs, 1994

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Moreover, the empowering character of this methodology is consistent with the personal and collective empowerment issues that are crucial for self-help groups. Finally, the sharing of control between researcher and participants in participatory research is very helpful in overcoming the reserve that a lot of groups have toward researchers—even toward the most ‘sensitive’ ones.\(^9\)

**My methodological choices**

Taking into consideration the methodological issues and complexities already discussed, I felt that my choice of methodologies in the present study ought to be flexible, in order to reflect the particularities of the self-help/mutual-aid field. My first concern was to be able to establish good relationships with the groups I approached, so as to be able to co-operate with them in the research project. Following the principles of participatory action research, there was constant communication between the researcher (myself) and the participants (group members), in the form of participant observation and the adversary hearing process. More specifically, right from the beginning of the study, I introduced myself to the groups and made it clear that my research intention was to learn from the groups and understand their ways of functioning. I also stated that I perceived myself as a mental health worker and a researcher; however, the purpose of my presence at group meetings was to have first-hand experience of these groups, and not to intrude and force ‘an expert opinion’ onto the groups. My frequent contact with the groups gave the members a chance to ask their questions about the project and to clarify with me any issues they felt were important. For instance, during a group meeting of the Fellowship of Depressives Anonymous, a member who had doubts about my attendance put forward the issue in the group; and this was a good opportunity to discuss members’ feelings toward me. In that particular case, the group argued that they were feeling positive about my participating in their meetings, and that they wished more professionals were willing to hear their views. Moreover, I kept ‘an open communication line’ with the groups during and after the study. I went back and visited a number of them, getting their feedback about the results.

As the main purpose of the study was to record systematically the psychosocial characteristics of self-help-/mutual-aid-group members—such as empowerment, social support and networks, helping processes, and group identification—I wanted to include quantitative measurements as a way of exploring a set of relevant variables. My aim was to keep the questionnaires as user-friendly as possible, to keep them as short as possible, and to avoid professional jargon. For that matter, I also ‘tested’ the selected set of questionnaires in a pilot study involving mental health service users attending a day centre.

Nowadays the combination of qualitative and quantitative methods is used more frequently by social scientists, who realise that a single methodology is not adequate to capture the complexity of social phenomena.\(^10\) My methodological design was an effort to tackle the difficulties mentioned by previous self-help researchers. For a more comprehensive approach, I adopted sociological as well as psychological perspectives of self-help groups in my analysis of their

\(^9\) Rappaport et al., 1985
\(^10\) Rabinowitz & Weseen, 1997

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processes and outcomes. Thus, the typology of political ideology I followed has a strong sociological influence; whereas, among the variables I chose to examine in order to evaluate differences between groups, there are psychological concepts such as mental well-being and helping group processes, and broader psychosocial factors such as empowerment and social support and networks.

**Challenges**

The unique features of research in the self-help/mutual-aid area urge the researcher to break from the traditional experimental designs widely used in the field of psychology. There is a need to have a mind open to a combination of research methods—quantitative and qualitative—in order to remain reflexive to the natural and spontaneous character of self-help/mutual-aid groups. However, this choice presents difficulties, as it can lead to contradictions. For example, my intention to study a set of individual and group variables in a quantitative manner led me to the use of self-completion questionnaires. The drawback of this choice was the fact that most self-help/mutual-aid group members were reserved towards professionals and their traditional methods of questioning, and I had to address their hesitation in completing the scales. On the other hand, my decision to collect information about the groups through participant observation led me to the process of asking permission from groups to attend their meetings. In order to do so, I often had to ‘defend’ my project and my research intentions against members’ criticisms, and help members overcome their distrust of professionals. To address these dilemmas, I tried to be as flexible as possible, given the limitations of time and resources. The selection of questionnaires was made according to certain requirements such as simplicity, jargon-free language, and relevance to the issues in question. Then I validated this selection in a pilot study where I had feedback from mental health service users and made changes to the questionnaires accordingly. Before administering the questionnaires to self-help-group members, I spent considerable time presenting the content of the scales to them, explaining the questions asked, and justifying their choice. During this discussion, I had an opportunity to answer people’s queries and address their doubts and objections. In any case, participation was voluntary. Finally, in order to be aware of respondents’ opinions, there was a last part of the questionnaires asking for participants’ feedback. The vast majority of respondents made positive comments about the selection of scales in relation to their clarity, their element of understanding, and their relevance to the research questions. My contact with self-help/mutual-aid groups became a valuable learning experience, as I had the opportunity to reflect upon—and reconsider—my research questions in the light of the discussions I had with members. Specifically, in order to establish their co-operation, I presented the project to them in detail, explaining the purpose of the study and asking for their help. This was an interactive process during which I, the researcher, shared my theoretical knowledge about self-help and my research questions with group members; and they, the participants, shared their experiential knowledge and their ideas about the study with me. The result of this process, which evolved throughout the project, was a relationship of collaboration based on mutual trust. Furthermore, the fact that research on self-help/mutual-aid groups is still in its early stages generated additional challenges: for example, there is a lack of research tools designed exclusively for this type of study. It is not always easy to compensate for this shortage by ‘borrowing’ tools from other related areas of
research. Existing tools used by self-help researchers have usually been created to examine only specific types of groups, e.g., Alcoholics Anonymous. They may not be so adaptable. An example of this difficulty is the questionnaire I used for the assessment of help-giving group processes. Although it was judged very relevant by group members, it is nonetheless heavily influenced by the theoretical assumptions concerning the functioning of psychotherapy groups. Therefore it is able to depict processes aimed at personal change better than those aimed at social change. Despite this weakness, all respondents reported a high number of helping processes occurring during meetings, and especially certain types, such as supportive and expressive ones. These findings show that the scale relates to the self-help experience, but that possibly there is a need for refinement of its items in order to assess processes emphasised in social-change groups, such as community activism and advocacy.

From the above examples, it is evident that research in the self-help area calls for inventiveness and flexibility in methodology. The researcher cannot rely on ‘traditional’ one-sided approaches; instead, as Humphreys and Rappaport (1994) put it very graphically, ‘self-help researchers can take many roads (research paradigms) on a common journey (knowledge about the phenomenon of self-help groups)’ (p. 217). Being rather ‘young’ as a research field, it presents the advantage of being yet boundless in the scientific approaches used by scholars—hence constituting an intriguing area for alternative research paradigms.

References

SPN Paper 4: “Where you stand affects your point of view”. 59

11 Self-Management in Bi-polar Affective Disorder
– Amanda Harris

Recognition:
Triggers and warning signs of a manic or depressive episode
**Action:**
Coping strategies and medication
Support networks and action-planning

**Maintenance:**
Maintaining healthy lifestyle
Mood diaries
Bringing it all together

**Principle:**
People with manic depression can become experts in mental health

**Aim:**
To equip participants to develop new strategies; monitor mood states; link thoughts, feelings and behaviours; and develop an alertness to mood variation

**Our facilitators:**
Effective self-managers
Untaken SMTP
Assessed against competencies
Development centre
Advance directive
Ongoing support
Open University training programme (City and Guilds)

**Current situation:**
34 courses run in England and Wales
Over 3000 participants
28 facilitators
Lottery funding 2001/2002
“Stepping Forward” Programme
Young Person’s Programme
Mood diaries
The Programme Findings

[Graph showing mean values over time for BDIA and BDIB]

Working Together – Issues:
User-led/Professionally led
Future funding issues
Support for facilitators (if user-led)
Professionals' understanding of the programme
Supporting, but not replacing, traditional services
Recognition that patients can be “experts”
Seamless support to users – not “them and us”

Strengths:
Power of role models
Honesty
Meeting others
Support networks
Common (lay) language through which to discuss MD
Less likelihood of power imbalance
Drawing on wealth of service user experience
12 “There is a Better Way”
- Tony Glynn

I want to tell you about a personal experience of some research that I was involved in back in 1999—research that completely changed my life. It was around this time that the Review of the Mental Health Act was happening; and it was suddenly realised that no-one had ever asked the people concerned what it was actually like to be hospitalised against their will. So Birmingham University and the Nottingham Advocacy Group got their heads together to see how this research could be taken forward. It was agreed that service users should be included in the design and structure of the research from start to finish, and this is where I came in. Along with four other service users, I was invited to work alongside three researchers from Birmingham University in planning the research and conducting interviews. What we wanted to achieve was to try and understand the impact of compulsory admission on:

- service users’ ‘careers’ within mental health services;
- relationships with mental health workers; and
- service users’ sense of themselves, their relationships with their families, and their lives in general after they have been discharged. (‘There Ought to be a Better Way...’ Barnes et al., 2000.)

This was brilliant, and—for the first time in a long time—I felt valued for my life experiences. But I never realised the effect that it would have on my life. I'll be honest with you: when it came to the interview stage, I was scared stiff. The reason for this was that, although we had shared a ward on many occasions, I still assumed that everyone who was held on section was ‘dangerous’. But that was about to change when I actually met the people concerned and talked to them. When I first met them, I mentioned that this was all new to me, and that I was probably more nervous than they were; from that moment on, any barriers that might have been there were broken down. The fact that I too used mental health services helped to develop a rapport, and my nervousness about interviewing meant that the interviewees didn’t themselves feel intimidated. I was riveted by what they had to say, and I came away from these meetings a lot wiser and a little angry. The experience of them telling their stories and me listening to them was an intensely moving one that both sides connected with; and although their accounts could often be ones of painful or humiliating events in their lives, there was a surprising amount of shared laughter—evidence of a degree of commonality of experience that underpinned the interview process. (Tew et al., 2000)

Conducting these interviews was inspirational for me; it gave me a new focus. It made me look at my own assumptions head-on and understand that it’s not the people who are dangerous; it’s the situation that they find themselves in. When you hear their stories of survival, how could you not admire these people? I have been hospitalised twice since this research, and on the first occasion I took the findings in with me. I firmly believe that the only reason I was able to do this was because—as a voluntary patient—I was less sedated, and there was nothing taken away from me. After some time I found myself comparing what was in the research and what was happening around me to see if anything rang true, and I
was quite surprised at how much did. The first thing I noticed was how some nurses who ‘shadow’ patients would always stay in the background about two metres away, as if the people in their charge had some kind of contagious disease. I could never understand why some staff, when observing someone, didn’t engage in any way. I found the environment on the ward was a very ‘don’t-bother-us-and-we-won’t-bother-you’ existence where it was almost impossible to get any ‘one-to-one’ time with the staff. This was reflected in the research. As one respondent said, ‘to get any attention, you have to approach the staff—but, because people don’t like interrupting, they “suffer in silence”’. Being in hospital is never an easy option for us—whether voluntary or sectioned—but it could be made easier if more staff found the time ‘to really listen to what we had to say’ instead of just observing and assessing. (Barnes et al., 2000) It wasn’t all bad: on the one hand, it seemed that there were staff who were obviously there just to do their clinical job of containment and control; but on the other hand, there were brilliant staff who remembered the social aspect of care, and who were much appreciated by us. It must be said that the most approachable people were student nurses, cleaners, and other patients.

You could see the difference between ‘voluntary’ and ‘sectioned’ status: I didn’t have someone looking over my shoulder all of the time. I could go to the ‘jolly trolley’ (medication) and say, ‘I don’t think I’ll need that tonight, thank you,’ whereas under compulsory admission ‘You can’t negotiate what medication you take, you’re just given it and, under section, you are forced to take it. That is wrong and it’s something that needs to change.’ Also, I could go to the toilet on my own. Something that still angers me every time I think of it is the “degrading” and “humiliating” observation of female patients by male staff on some wards. It does happen and it surely raises the question, “How would you like this to happen to you?”

Between hospital admissions I was given the opportunity to study Community Mental Health at university, which set me up very well for my second admission. When I was first admitted I unconsciously became an advocate. I didn’t plan it; it just happened. With my new-found wealth of knowledge around such things as the National Service Framework and the NHS Plan and its ‘Best Practice’, I wanted to share that knowledge. Much to the annoyance of the staff, I became an advocate for everything that moved. I’m not sure if this helped the system in any way, but I am positive that some people came out of that place with more information about basic human rights than they had when they went in. I became an advocate on the outside; but I soon found out that if you want to be taken seriously, you don’t mention that you are a service user (especially in ward rounds).

When we conducted the interviews, we asked people if they could think of anything that might ease the distress of hospital admission. Advocacy was rated very highly. ‘Having an advocate made a big difference. He was very helpful and supported me. After using an advocate, I found workers were more likely to listen to what I had to say.’ In my experience, advocacy has always been a very good idea—but nobody wants to pay for it. Something else that was rated highly was a safe environment which offered timely and responsive relationships with mental health workers, and that is where I am now. I work for a brilliant organisation
called CHANGE (Choice and Alternatives for Growth and Experience), which is service-user-led and service-user-run. We have two crisis-and-recovery houses in Birmingham where we offer an alternative to hospital admission. It is a 24-hour, 7-days-a-week service; we work in partnership with local Home Treatment and Assertive Outreach teams so that our guests’ clinical and social needs are catered for. The atmosphere in the houses is a therapeutic one where safety is uppermost, and I think this is made possible by that ‘commonality of experience’ I mentioned earlier.

This research changed my life by changing my attitude. One of the most rewarding things for me today is to stand up alongside those people I interviewed and deliver mental health training to other people in order to change their attitudes. Such is the power of the research that, on occasion when we were delivering Approved Social Worker (ASW) training, some people became very upset and said, ‘If that’s what happens, I don’t want to become an ASW’. It took a long time for my co-trainer and I to convince them that they were actually the kind of people who should become ASWs. Although only an exploratory pilot study of 11 people’s experiences, the research takes into account 40 separate instances of hospital admission and I firmly believe that it should be taken a lot further so as to include more diversity. Another very positive outcome of this research is that it paved the way for Suresearch to be established. Suresearch is an ever-growing network of service users, academics, and practitioners who work together in research and education. Based at Birmingham University, it enables people like me to get a life away from passive service usage and to put some worth back into their existence. If we’re talking about ‘emancipatory research’, this is not at all bad for an Obsessive Compulsive Bricklayer (OCB)!

References:

Details of Organisations Mentioned:
Choice and Alternatives for Growth and Experience (CHANGE)
13-15, Gravelly Hill North, Erdington, Birmingham B23 8BT

Suresearch, Department of Social Policy and Social Work,
The University of Birmingham, Edgbaston, Birmingham B15 2TT

13 Strategies for Living: Presentation by Strategies for Living (S4L) at the Mental Health Foundation (MHF)
Stephanie Wells and Sarah Wright

Stephanie Wells:
We are here to give an overview of the part of our work that involves supporting user-led research projects around the UK. I will start by giving a context to our work; then Sarah will go into more detail about one particular project; and we will finish off by listing some of the challenges and achievements of our experience in terms of some key features of emancipatory research.

When we employ the term ‘users’, we include users and survivors—people who use, or who have used, mental health services; those who consider themselves to be survivors of either the psychiatric system or experiences of distress; and those who have had significant experience of mental or emotional distress.

Current work
We are now nearing the end of a three-year community-fund-backed project which involves supporting 12 user-led research projects around the UK: five in England, four in Wales, two in Scotland, and one in Northern Ireland. The individual reports—as well as an overall report of the S4L team’s experience of supporting user-led research—were published last autumn.

This programme of work is built on the experience and findings of the first phase of our work, in which S4L undertook 71 in-depth interviews with people who had experienced mental distress—to look at common themes and most helpful supports. The findings were published as Strategies for Living

This was complemented by support to six small-scale locally based user-led research projects. Topics included:
- user-groups and empowerment;
- auricular acupuncture; and
- benefits of mosque for Muslim men with severe mental health problems

Project selection
I’d now like to talk about the selection of the projects we are supporting. The selection criteria were based on:
- the themes identified in the S4L report, and the experience of supporting projects; and
- the views and experiences identified during a UK-wide consultation process with user-groups, including issues such as
  - access to a range and choice of treatments;
  - provision of specific culturally aware services; and
  - initiatives towards social inclusion

For the purpose of selection these became broad topic areas such as:
- personal coping strategies
- helpful relationships
- alternative treatments
• practical empowerment

We invited anyone with experience of mental distress and/or using services to select their research question and submit a proposal. No standard of formal education or research experience was specified, as full training was to be given.

To make the project as accessible as possible, we advertised through Mindlink, Diverse Minds, Scottish User Network, Mind Cymru, our existing contacts, and other user-groups—including gay and lesbian and Black and minority ethnic groups. We received over 100 applications, and—using the aforementioned criteria—these were short-listed by the S4L team, all of whom have experience of mental distress.

The final selection of 17 projects (six in England, six in Wales, four in Scotland, and one in Northern Ireland) was made by the S4L Advisory Committee—made up of users, some of whom had research experience. The Foundation’s trustees ratified the final selection.

Topics selected included:

• service users’ experiences of accessing the benefits system;
• living with domestic abuse;
• resources in the community for Black women in Bradford;
• return to work after a period of illness;
• relieving distress in hospital settings; and
• leave from hospital for detained patients

Funding
A point about funding: community funding does not allow for any money to be passed on. The MHF provided £2000 in research expenses for each project, but unfortunately we were unable to pay the researchers for their time. We recognise this as a major inequity, and something we will seek to redress in future work.

Each lead researcher signed a grant agreement form, which set out the conditions under which s/he would receive the grant—payable in instalments over the two years. These conditions included:

• the terms under which the Foundation would offer support and training; (Training was given on all aspects of the research process. And grant instalments were to be withheld if the researcher failed to attend two consecutive training sessions or meetings, or failed to keep in regular contact with his/her support worker.)
• the accountability of researchers: first to the participants, and second to the Foundation;
• the right of the Foundation to access materials relevant to the project; and
• the Foundation’s ownership of the final report—although the researcher has intellectual ownership of the project and is free to write other material such as articles
Sarah Wright:
One of the projects that I have been supporting is an example of research which has attempted to take on the values of emancipatory research. My role in terms of support is to provide and deliver a training programme as well as to work alongside all the research projects to their completion. This can mean giving advice on all aspects of the research, sometimes working with researchers on the research, and also sometimes providing emotional support.

The project is called ‘Dancing for Living’ and is an exploration of women’s experiences of 5 Rhythms Dance and its effects on their emotional well-being.

Five Rhythms Dance is a kind of free movement that takes people through five rhythms: flowing, staccato, chaos, lyrical, and still. The belief is that emotions and spirituality from internal depths of consciousness can be freed.

Ethos
In Jan Wallcraft and Peter Beresford’s chapter in *Doing Disability Research*, called ‘Psychiatric System Survivors and Emancipatory Research’, they talk about a research paradigm that is interested in

‘survivors speaking and acting for themselves; improving their lives and liberating themselves from an oppressive psychiatric system; changing and equalising relationships between research and research subjects, and developing survivors’ own knowledge collectively’.

One of the main aims of the Strategies for Living project has been to develop and share knowledge with other users and survivors. This is done by building the capacity of survivor-researchers, and by sharing their research findings about alternatives to mainstream treatments extensively with survivors and users.

As pointed out in Wallcraft and Beresford’s article, the thing which is different about survivor research lies in the choice of what is to be researched and the perspective it comes from; and emancipatory research is the most developed in terms of research into alternatives.

Out of five projects I have been supporting, this one in particular is, I think, a good example of research into alternatives.

I think it unlikely that this research proposal would have been funded elsewhere; it has been looking into something that is very far outside the mainstream.

There have been three researchers involved in the project. One researcher did have research experience and used 5 Rhythms Dance herself as a strategy for living and for coping with her mental distress. The other two women involved had experience of neither 5 Rhythms nor research.

Being given an opportunity to research something of this nature—something close to one researcher’s heart— was an empowering start.
The training in research skills is done in a facilitative way, sharing knowledge with the new researchers as well as introducing them to new skills and ideas.

Although there are the power imbalances between myself as paid worker and the researchers as volunteers, there is still an ethos of working together—sharing knowledge rather than instructing. I may have had some skills in research to share, but researchers had their life experiences. These will have given them many skills required by a researcher: knowledge of their local areas, knowledge of their subject, and ideas about how they wanted to do the research—which would be discussed and agreed together, though such ideas had to fit into Strategies’ ethics and ethos as well.

**The levels of participation in the project**

The researchers in this project have written in their first draft report that they are breaking down power dynamics by conducting their research in the way they have. All three researchers participated as dancers and research subjects in the process.

The methods used were:

*Peer pair interviews:* dancers paired up and asked each other six qualitative questions about the dancing.

*Writing and drawing:* all dancers were encouraged to keep a diary, or write poetry, or use pictures to depict feelings/experiences of dancing.

*Group discussions:* the three researchers ran three focus groups.

The researchers felt that by participating in the research themselves, they achieved a more relaxed atmosphere and enabled participants to be more open and honest. A quote from their final report states that there was ‘a nurturing atmosphere’. All participants received copies of the transcripts from their focus groups and peer pair interviews, and were invited to make comments or even to withdraw anything that they did not feel was an accurate representation.

Participants are also having a reunion. Having been sent copies of the draft report beforehand, dancers will be invited to give comments and feedback on the findings and research process. The dance teacher has also been invited to write a short piece for the report about her experience of being involved in the project.

**Ethical Considerations in the project**

As well as providing full information to all participants and gaining informed consent, the researchers offered childcare payments to any of the women who would be prevented from taking part because of childcare responsibilities. They also offered a counsellor for any of the women who felt they needed emotional support because of issues arising from their involvement in the dance workshops. In this particular project the participants were not paid for their time; in fact, women paid (on a sliding scale) to take part in the project. This was because it was felt that the women would gain from the dance instruction. It was also about costs: employing the dance instructor took more than half of the research budget.
But this did not put women off taking part: the workshops actually ended up with a waiting list.

**Issues for the researchers**

It has not all been smooth sailing. One researcher had a job throughout, and had to juggle this with the research, which itself called for a huge commitment. This shows the inequity of not paying researchers for their time. Another researcher had periods of mental distress during the project, and found aspects of the research particularly demanding. However she also went on to say,

‘*I wasn’t paid in money to take part, but I feel was paid emotionally and spiritually*’.

The third researcher has gained in confidence through this and other activities she has been involved in, and has now gone on to her first paid employment. So, in conclusion, we do feel that this one project shows some significant moves forward to research of an emancipatory nature.

**Stephanie Wells:**

**Summary of challenges and achievements in our work supporting user-led research:**

**Challenges**

- Lack of payments to researchers
- Grant instalment schedule
- Support *versus* funder dynamic
- Power imbalance

**Achievements**

- Agenda-setting and the project-selection process
- Independent from services
- Researchers maintain the intellectual right to the data
- Empowering nature of the research experience
- No knowledge base required; ‘experts by experience’ ethos
- Skills and confidence developed
- Acknowledgement of subjectivity
- Involvement of participants in research process

For more information contact Strategies for Living on:
Telephone 020 7802 0335
Email swells@mhf.org.uk
Website at www.mentalhealth.org.uk

**APPENDIX – ADVANCE STATEMENT AND GUIDANCE NOTES**
Acknowledgement

Mental Health professionals and service users developed this Advance Statement jointly. In particular, the Cambridgeshire & Peterborough Mental Health Partnership NHS Trust would like to thank Phil Alsop—Secretary of Cambridge Manic Depression Fellowship Self-Help Group—for considerable assistance, given voluntarily throughout the project.
Introducing your Advance Statement

“MAKING IT BETTER NEXT TIME”

A shared way to manage your mental health more effectively

INTRODUCING YOUR ADVANCE STATEMENT

What is an Advance Statement?
An Advance Statement is a way of ensuring that if you are ill again, everyone concerned knows the best way to treat you. It means you can let others know what medical treatments work best for you (or least well). You can also prepare plans so that your family, home, finances, and work are dealt with in the most helpful way.

What will it entail?
A member of your Community Mental Health Team—usually your Care Coordinator—will help you think about ways to deal with a setback in your health. This may take place over a number of meetings. It will cover medical treatment, your home and family, and finances. It will ensure that your wishes are known.

The actions you agree will be recorded on a special form.

When will this take place?
It is best to plan when you are well. A good time might be a few weeks after you have come out of hospital and your health has settled down again. You can start to think about these things any time, though, and make notes for later.

Does everyone have to have one?
You do not have to agree an Advance Statement. However, it is a good idea for anyone who has had a serious mental health problem that might recur. It is there to help you to cope better next time, and to make sure your wishes are respected.

“I feel more secure knowing that some of the worst problems have been thought about. I just know it will be better next time.”
Can I make people treat me as I want?
You cannot make doctors or nurses do anything against their medical judgement. You cannot force anyone to do anything against his or her will – but all members of the Mental Health staff want to respect your wishes and do what is best for you.

“I was really moved by how everyone wanted to respect my wishes (so long as they weren’t too far out!”

So what’s in it for me?
If you think ahead and prepare for another episode of illness, it should be less of a shock. Medical staff can treat you in a way that takes your views into account. You can also ensure that home, family, finances, and work suffer as little as possible. That will help you to get back on your feet again as soon as possible.

The Advance Statement is available from your Community Mental Health Team.

To find out more, ask a member of the Team.

You may also wish to file your Care Plan (CPA) in this binder
ADVANCE STATEMENT – SOME NOTES TO HELP YOU

1) What is an Advance Statement?
It is a statement of how you want to be treated if you become ill again. You decide in advance of your illness (i.e., when you are well) what you would like to happen to you. These decisions should be respected by the medical profession unless there are good medical or legal reasons for not doing so (e.g., if you are on a ‘section’ of the Mental Health Act). They should also help to ensure that you get the most suitable treatment.

2) What is involved in making an Advance Statement?
You can develop your statement jointly with your Care Co-ordinator. He or she can help you think it through. Attached is a standard form, which you are encouraged to use. It is also best to complete the statement in consultation with your Care Co-ordinator and doctor.

3) What should you do once it is written?
You need to put it on record by getting a copy filed in your medical notes at the hospital and/or lodging one in the community. (In the latter context, you may want a member of your family to have a copy of this statement, or you may want to give a copy to the person who cares for you.) This should ensure that it comes to the attention of people treating you in an emergency.

You will also need to review your Advance Statement regularly to make sure it is up to date. This is likely to apply particularly if there is a major change in your condition or treatment, or if your family circumstances change. An annual review is a good idea, and—ideally—this could be done as part of your preparation for your CPA review.

4) What should you include?
The most important thing is for you to think carefully of what will most benefit your condition and circumstances. We are all different, so decide what you want. Do not just copy someone else. The notes below suggest some of the most important items to include:

Working out your Advance Statement
Here are some ideas for what you may want to think about. There are spaces for them on the attached form if you wish to use it:

a) Medical History
It is especially useful for medical staff to know your history. Make sure you give details of when you have been in hospital and where. Say also if you were admitted under a ‘section’ or informally.

It is also very useful if you can make clear what signs best indicate that you are becoming unwell. Think how you differ from when you are well (e.g., sleep patterns, behaviour, your mood, how you are with people).
There may be a family member or friend who knows when you are becoming ill—someone you trust to discuss your health with medical staff. Make sure that you give details of whom to contact, and make it clear that medical staff may (if you consent) discuss your health with that person.

b) Future Treatment
What would you be prepared to accept if it were offered? Is there anything you would be reluctant to accept? What about a new or experimental drug? What about Electro Convulsive Therapy (ECT)? What about injections?

c) Other Medical Conditions
Do you have any other illnesses, allergies, or health problems that you want medical staff to know about (e.g., diabetes, asthma, or penicillin allergy)? Are you on any drugs that must be taken continuously? Have you had a very bad reaction to a treatment?

d) Personal Care
Are there any dietary or personal requirements that you want to make known? For example, are you allergic to certain foods? Are you on a vegetarian or reducing diet? Are you willing to be examined medically by a member of the opposite sex? Are you pregnant or a nursing mother? Does your religion require you to observe particular practices?

e) Contacts
Make sure you consider who would need to be contacted if you became unwell again. Do these people know what to do? Unless you clearly give your consent, medical staff may not be able to discuss important medical issues with them. Make it clear to whom they may and may not speak.

f) Keeping Things Running
Who would you like contacted in an emergency? Make it clear whether or not you consent to medical staff letting them know about your health and treatment. Say how to contact them.

Have you arranged for someone to look after your home? What about children, if you have them? What about pets?

How will your finances be taken care of? Would it be prudent to have credit cards or chequebooks put away safely if you are ill? What about bills, and other payments like insurance? What about collecting wages or benefits? Who do you want to help?

If you are in employment, how would you want work notified that you are ill? Do they know you have a mental illness? What should they be told?

(Remember that you could be taken ill away from your home; or in an emergency you could be treated by staff who do not have your notes. In those circumstances, the information given here could be very important. Show a copy of your Advance Statement to the people who treat you).
ADVANCE STATEMENT

This form is to help you to think ahead and prepare for a time when you might be ill again. On the following sheet, you will be able to say what you want to happen. This sheet is to record important personal and medical details and to make sure that medical staff and other helpers use only your most up-to-date plan.

Complete the form below. Leave blank any items that do not apply to you. Where you see an asterisk (*), delete as appropriate. Continue on another sheet of paper if you need more room.

Name: __________________________ Date of Birth: __________________________

Address: __________________________ Telephone: __________________________

Hospital Number (if known): __________________________ Diagnosis (if known): __________________________

My Psychiatrist is: __________________________ My Care Co-ordinator is: __________________________

My Social Worker is: __________________________ My GP is: __________________________

I live alone*/I live with the following people:

This document should be reviewed with your key worker shortly before your CPA review. You may amend it at any other time, of course, if you feel the information is out of date. Please date and initial any amendments you make in the space below.

Please also decide who else—apart from your key worker—should hold a copy of this plan. We can then help you to ensure that named individuals also receive up-to-date copies of your wishes.

<table>
<thead>
<tr>
<th>I last amended this plan on the date below</th>
<th>The following people also have copies of this plan (give details):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date: __________________________</td>
<td>Your initials</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Medical History

(Give here a brief description of your illness including the main symptoms and treatments)
Have you been treated for this condition in hospital before?
If so, which hospital?
When were you there, approximately?
Were you an informal patient?
Are there any warning signs when you are becoming ill?  YES/NO
If YES, please say what they are:

Which other person is the best guide to when you are unwell?
(Make sure you give that person’s contact details on the back page.)
What appears to make your symptoms worse?
What appears to make your symptoms better?
Any other relevant information:

ADVANCE STATEMENT  NAME:________________________

If I become unwell again, I ask that my wishes expressed below be respected:
(Mention here details of any treatments you are taking and those which are most helpful or unhelpful)

I am currently taking the following medication:

Of the treatments I have taken, the following have been most helpful, for the reasons stated:

Of the treatments I have taken, the following have been least helpful, for the reasons stated:

I have particularly strong feelings about the treatment mentioned below: (Give details of any treatments you especially prefer to use or prefer to avoid, with reasons)

(Mention here any other health conditions, allergies, or treatments)

Please also bear in mind the following aspects of my health and treatment:

(Mention here any special needs or requirements; for example, dietary, religious, or personal needs)

Please also respect the following in the way I am cared for:

KEEPING THINGS RUNNING

SPN Paper 4: “Where you stand affects your point of view”.
(Mention here any other requests. They might include plans for taking care of family, work, pets, finances, or your home. Include names and contact details of people you want to be contacted)

Please also do the following for me:

(Finally, if there are people or organisations you do not want contacted, please give details)

Please do not contact the following people or organisations:

SIGNED: 

NAME IN CAPITALS: 

POSITION: 

DATE: 

WITNESSED: 

NAME IN CAPITALS: 

POSITION: 

DATE: 

Further Help
If you want any further help with completing an Advance Statement, you can ask your professional worker. It can also be a good idea to discuss it with a relative or friend. A solicitor would be able to help if the legal aspect concerns you. For general mental health information, you may want to access the following:

www.cambsmentalhealth.info
www.cambsmh.nhs.uk/welcome.htm

On these sites, you will find local information and links to national information.