the abilities and skills of (ex-) users and survivors are acknowledged and used in proper ways.

Jan Wallcraft

User-led Research to Develop an Evidence Base for Alternative Approaches

The Role of Research in Mental Health

Mental health research does not appear from a void, but is carried out by people with a life-history and a set of beliefs and motivations. The purpose of mental health research is to create a solid foundation of knowledge, on which to base treatment and services. But knowledge can never be free from value-judgements, beliefs, attitudes and experiences. I have found it useful to look at the models (otherwise known as paradigms, world-views, or discourses) that underpin mental health research, as that enables better awareness of the political aspects of research, and the power struggles over what knowledge will be most socially valued and receive the greatest funding.

The most influential model is the biomedical model of mental illness, which still dominates most funded research. The biomedical model has been described as a mechanistic and reductionist model, based on Cartesian philosophy and Newtonian science (Capra, 1982). Research is as far as possible carried out in clinical settings where treatments can be tested without interference from extraneous factors. Research is largely based on statistical methods.

The psychosocial model of mental health and illness which is more holistic and dynamic and includes a wider range of interacting factors, is gaining ground as, in most countries, large asylums are being closed and people with mental health problems are living most of their lives in the community. Psychologists, community psychiatric nurses, occupational therapists, social workers and other professionals are gaining status in relation to doctors and

many are carrying out research using a psychosocial model. Qualitative research based on interviews and questionnaires is more likely to be used in the psychosocial model.

The third, emerging model, I call the self-advocacy model, developed by service users/survivors and their allies, challenges the power of professionals and their right to define and treat so-called mental illness. It emphasises the value of personal experience in knowledge creation and the importance of regaining power and control over one's own life. Many people who have survived severe mental health problems have been able to find meaning in their experiences and have worked to create and research alternatives to psychiatry. Self-advocacy research often needs more empowering methods of doing research, and some have been found in the work of the disability movement, which has developed concepts of emancipatory research. This, at its best, ensures true power sharing, so that research workers and research subjects are paid equally for their time. Everyone shares in developing the research, carrying it out, writing and publishing it, so that all gain power and knowledge from the process. Methods include action research, narrative research, indepth interviews and focus groups.

Service user/survivor researchers do not all have the same knowledge and beliefs, but we usually share a commitment to addressing the power imbalance between researcher and subject, and between doctor and patient. Some of us are academically qualified, others have learned research skills in short courses or simply by doing it. Some started out as researchers and then became service users; some, like me, began as service users and learned to do research to understand our experiences better.

We usually seek to remove the mystery from psychiatry and to find out what psychiatrists know. We also want to understand the limits of their knowledge. We explore different forms of support and help in real life contexts rather than merely comparing the difference between one drug with another drug in treating clinically-defined symptoms. Clinical trial methods are criticised by service user/survivor researchers because they limit the kinds of questions that can be asked, and the outcome measures that can be used. In clinical trials, the aspects of "mental illness" and recovery that can be numerically or statistically measured become the most important aspects, simply

because they are measurable and not because they are necessarily the most important to service users/survivors.

My own path to becoming a researcher was part of my journey towards reclaiming my own life. Ten years after I left the mental health system, I went to college to get a degree. Having spent years trying to piece together my shattered memories, I was curious to know more about the effects of ECT on the brain. The medical literature I read rarely questioned the ethics of electrocuting mad brains, but I found a wonderful book in a socialist bookshop, *The History of Shock Treatment*, by a survivor from the US, Leonard Roy Frank (Frank, 1978). This is a collection of writings from every perspective about shock treatments from insulin coma onwards, including many personal testimonies and writings by service users/survivors. I learned from Frank that there is no simple path towards scientific truth, especially in such a complex field as psychiatry. At one point, early in the history of ECT, 52 different medical theories about how it worked were listed. The problem is that, in conventional psychiatry, the patient's perspective has been automatically discounted because within the discourse of "mental illness" we are not regarded as reasoning human beings.

It is only since service users/survivors of psychiatry became an international movement that we have been able to demand our legitimate place in knowledge creation, but our movement is not yet strong enough to call for a revision of the accumulated psychiatric knowledge of the past 150 years or to force a major change in the methods of doing research.

At college and outside it, I began to meet other people with personal experience of psychiatry. Women were saying that the hospital is not safe for them. Many (like me) had experienced sexual abuse in hospital (in my case by a psychiatrist), so I became concerned with how we can help ourselves without psychiatry. I studied alternative therapies and became a qualified aromatherapist and healer. I learned co-counselling and joined self-help groups. I tried various forms of psychotherapy and counselling. I helped to set up a "women only" crisis service. I learned that both men and women have the same needs for respect, dignity, safety, self-esteem, empowerment, and trusting relationships.

I heard and read hundreds of service user/survivor stories over the years and I learned that we could help each other to cope even with the most severe mental health problems. I went on to do a Ph.D. in which I developed my skills as a service user/survivor researcher. In the U.K., there are a growing number of service user/survivor researchers within and outside the academic system. Service user/survivor led research has been supported by voluntary organisations such as MIND, the Mental Health Foundation, and the Sainsbury Centre for Mental Health.

I have been involved in several pieces of research alternatives to psychiatry. The biggest and most influential project was the four-year Strategies for Living service user/survivor research programme at the Mental Health Foundation (Faulkner & Layzell, 2000). This was managed by a service user/survivor researcher, Alison Faulkner. Funding came from the National Lottery. The research was overseen by an advisory group of service users/survivors.

The first stage of this programme was a large survey called *Knowing Our Own Minds* (Faulkner, 1997) about what people with mental health problems think about mental health treatments and therapies, and what kinds of personal self-help strategies they find helpful. Over 400 responses were received. Based on the findings, the Strategies for Living research was designed to find out more about how people with mental health problems managed their own lives.

I was appointed to lead a team of researchers, all of whom were service users/survivors, to carry out 71 in-depth interviews with service users/survivors around the U.K. about the supports and strategies they found helpful. We developed a topic guide with a series of open-ended questions about the role of mental health services, talking therapies, complementary and alternative therapies, spirituality and other forms of help. The interviews were taped, transcribed and analysed.

The strongest theme to emerge from the research was the importance of relationships with other people, in all their different forms, including relationships with professionals. Other strategies and supports found helpful were: medication, complementary therapies, religious and spiritual beliefs, self-help strategies, sport and physical exercise, and creative expression. We asked what was most important about these different supports, and the main

themes were: being accepted, sharing experience, finding meaning or pur-
pose, and finding ways to take more control over one's life, and achieve
peace of mind. Coping strategies could be grouped into categories: on-going
survival strategies, crisis or life-saving strategies, symptom management,
and healing strategies. Different types of support would fit different types of
strategy. We were able to show that people create their own strategies for liv-
ing with mental health problems.

The report recommended that mental health professionals, service provid-
ers and policy makers should recognise that persons with mental health prob-
lems develop their own expertise based on personal experience. This exper-
tise must be supported and valued. Mental health organisations were urged to
disseminate information about the strategies that people find helpful and to
encourage and support people in managing their own lives.

The "Strategies for Living"-programme (Nicholls, 2001) also funded,
trained and supported service users/survivors to carry out small scale re-
search projects. These included:

• An evaluation of peer support at a drop-in centre. People said the drop-in
  centre motivated them to go out and meet others. They valued relation-
  ships, companionship and the empathy and understanding they received.

• A study of ear acupuncture at a women's mental health drop in. Women
  found the treatment helped them relax and gain confidence. Two partici-
  pants came off antidepressants during treatment. Several said the treatment
  had raised their awareness of the possibility of alternatives.

• An evaluation of the role of attending mosque in the lives of Muslim men
  with mental health problems, mosque was seen as an important place for
  men to connect with others of shared faith and prayer was soothing to the
  mind and heart.

A larger service user/survivor-led project supported by Strategies for Living
was *Life's Labour's Lost* (Bodman, *et al.*, 2003). This was a survey of 56 per-
son's experiences with losing employment due to mental health problems. It
looked at the importance of employment in people's lives, how the loss of oc-
cupation affects people, how they re-form their lives and what helps them to
find new occupation.

The report found that support was needed to help people understand and cope with their mental health problems to re-establish an "ordinary" life, find activities and occupations, try new things and regain hope and confidence. They also valued practical support with the stress of going back to work. People's stories told of difficult journeys with many ups and downs along the way. A particular job might be appropriate at one stage but not at another. A surprising finding was that many persons' sense of self changed for the better despite, and because of, their experiences. Some people reported positive changes in their values and priorities: they became clearer about what is important in their lives, developed greater understanding of others, and drew on their inner strength to create and rebuild more balanced and healthier lives. The researchers said that "such outcomes might be more common in society if people with mental health problems were included and supported more effectively. This would mean more people could contribute at less personal and social cost."

For the service user/survivor researchers who carried out the small projects, this was an important learning experience. Most of those involved in this programme were new to research, and they valued the training they received and the confidence and sense of competence they gained from doing the work. Several went on to do more training, others assumed new roles in local voluntary projects or paid work. Some have continued to develop their own personal coping strategies and help others to do so.

Another work that emerged from the Strategies for Living project was a report, *Healing Minds* (Wallcraft, 1998). I examined the evidence for a range of complementary and alternative therapies in mental health, including acupuncture, homeopathy, nutritional remedies, aromatherapy, massage and spiritual healing. I found clear evidence that service users/survivors wanted alternatives and valued them when they received them, in particular the lack of so-called side effects, improved feelings of relaxation, optimism and well-being, and being treated as a whole person. I found that despite some research showing that complementary therapies can reduce the need for psychiatric drugs, there is currently not much investment in doing more research, or in providing complementary therapies.

One problem is that randomised, controlled trials cannot easily demonstrate the aspects of complementary therapies that are most valued, for instance, the aspects of empowerment, choice, respect, individual treatment and healing partnership that come from working with a holistic practitioner. The dominance of the biomedical and psychosocial model in research makes it difficult to demonstrate the value of these therapies, and the lack of evidence for their value means that service providers do not provide them. However, in the U.K., there are signs that attitudes towards research in mental health are changing, with more qualitative methods being used and more involvement of service users/survivors in research priority setting.

I was involved as a research consultant in a recent investigation of coming off psychiatric drugs. This was a service user/survivor-led research project commissioned by the national organisation MIND (Read, 2005). As in the Strategies for Living project, a team of service user/survivor researchers were recruited to do the work. The team carried out 204 short telephone interviews, and interviewed 46 people in depth using a topic guide.

SSRIs (selective serotonin re-uptake inhibitors) are supposed to be easy to withdraw from; however, the researchers found that people had more difficulty coming off these antidepressive drugs than those on mood stabilisers (e.g., lithium or carbamazepine) or neuroleptics. The longer people were on any type of psychiatric drugs, the harder it was to come off.

Two-thirds of those who came off neuroleptics or mood stabilisers did so against their doctor's advice or without telling their doctor. It was found that doctors could not predict which patients would be able to come off successfully. Those who stopped taking psychiatric drugs against their doctors' advice were just as likely to succeed as those who came off with physician agreement.

The forms of support found most helpful were: support from a counsellor, a support group or a complementary therapist, peer support, information from the internet or from books, and activities such as relaxation, meditation and exercise. Doctors were found to be the least helpful group to those who wanted to reduce or come off psychiatric drugs.

The benefits of coming off psychiatric drugs included: better mental ability, taking back personal power and control, feeling more alive, and feeling good about managing without psychiatric drugs.

Following this study MIND (the organisation who commissioned it) has changed its standard advice to patients. Historically, their advice was not to come off psychiatric drugs without consulting a doctor first. MIND now advises people to seek information and support from a wide variety of sources. MIND also gave evidence based on this report to a government committee looking at mental health legislation, and plans to use the report to support the case against compulsory treatment in the community. The results of the MIND study confirm the international reports of experiences, which Peter Lehmann as editor gathered in *Coming off Psychiatric Drugs: Successful Withdrawal from Neuroleptics, Antidepressants, Lithium, Carbamazepine and Tranquilizers* (1998); this was the first book on this topic to be published in the world.

Conclusions

Knowledge created by service user/survivor researchers is based on a different value system from that of professionals. The key values for service user/survivor-led research include a commitment to change, expertise based on personal experience, countering stigma, redressing power imbalances, and desired outcomes such as self management and recovery of a satisfying life.

Involving service users/survivors in setting priorities, designing and carrying out research is likely to result in better quality research on more relevant topics. Service user/survivor-led research such as Strategies for Living can ask questions that are independent of existing services and treatments. For instance, spirituality and mental health emerged as important to people and led to further work on the subject. There is some evidence that people interviewed by service user/survivor interviewers have a better experience of the research process, feel more heard and understood, and are more likely to open up and give more information. Service users/survivors often find the process of doing research empowering:

> By focusing on the research process as much as on the outcomes, it
> aims to enable service users/survivors to take part in carrying out

research while gaining skills and confidence in the process. It aims
to be inclusive and informative, ensuring that people who take part
as research participants are kept fully informed of the results and of
any action subsequently taken. This is rarely the case with tradi-
tional research (Faulkner & Thomas, 2002, p. 2).

Methods, such as narrative research carried out by service users/survivors
who are likely to listen with genuine understanding and empathy, can get
closer to the meaning of people's experiences. Experiences, such as hearing
voices, cannot be objectively measured and diagnoses often explain little
about individual differences, strengths and weaknesses that might be needed
to ensure the most relevant support.

Service users/survivors in the U.K. are slowly gaining the confidence to
challenge in particular the dominant biomedical model of mental health. As
more of us gain qualifications in research, we are finding the courage and the
support to carry out research with different underlying assumptions about the
causes of mental distress. We take our own expertise through experience as a
starting point. In doing this, we adapt research methods to fit an attitude of
partnership and equality with those we involve as researchers and partici-
pants. Service user/survivor-led research into alternatives is one of the means
by which we contest the discourse of psychiatry which negates our human
rights.

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Andrew Hughes

Preparing People for User/Survivor Involvement Work in Mental Health and Social Care

After some stays in psychiatric hospitals, which included compulsory treatment, I began to be involved in the self-advocacy movement and to provide the occasional "patient perspective" and critique of mental health service provision during this time at conferences and training events. Involvement in local MIND organisations followed in 1988, and then, together with Anne Plumb and Tony Riley, I founded the Distress Awareness Training Agency (DATA), currently the U.K.'s longest established survivor training group.

I am happy to base my use of the term user involvement on the definition developed for the *On Our Own Terms* report, written by Jan Wallcraft and her colleagues:

> The use of the term "user involvement" is used in this report to mean the various ways in which mental health service users/survivors are helping to change mental health and social services. This often works through service users/survivors becoming members of committees along with professionals and people from voluntary organisations, though it can include a number of other ways, such as conferences, discussion forums, open days, service users/survivors acting as paid consultants, or professionals visiting user/survivor groups (Wallcraft, *et al.*, 2003, Appendix 1).

To these activities I would add the training of mental health workers and students by service users/survivors, and service users/survivors auditing, monitoring and researching mental health and social services.

Jan Wallcraft

User-led Research to Develop an Evidence Base for Alternative Approaches. The Role of Research in Mental Health

in: Peter Stastny & Peter Lehmann (Eds.), *Alternatives Beyond Psychiatry*, ebook, updated edition, ISBN 978-0-9545428-3-2 (EPUB), ISBN 978-0-9545428-4-9 (Mobi Pocket), ISBN 978-3-925931-57-4 (PDF), DOC (Word file, no ISBN), Berlin / Shrewsbury: Peter Lehmann Publishing 2018 [Information about the ebook see http://www.peter-lehmann-publishing.com/without-ebook.htm]. And in: Peter Stastny & Peter Lehmann (Eds.): "Alternatives beyond psychiatry", ISBN 978-0-9545428-1-8 (U.K.), ISBN 978-0-9788399-1-8 (USA), Print edition, Berlin / Eugene / Shrewsbury: Peter Lehmann Publishing 2007, pp. 342-351 [Information about the book see http://www.peter-lehmann-publishing.com/alternatives-beyond-psychiatry.htm]

Έρευνα από την πλευρά των άμεσα ενδιαφερομένων για την τεκμηρίωση εναλλακτικών θεωριών. Ο ρόλος της έρευνας στο ψυχοκοινωνικό σύστημα

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in: Peter Lehmann & Peter Stastny (Hg.): »Statt Psychiatrie 2«, E-Book, aktualisierte Auflage, ISBN 978-3-925931-46-8 (EPUB), ISBN 978-3-925931-47-5 (MobiPocket), ISBN 978-3-925931-58-1 (PDF), DOC (Word-Datei, ohne ISBN), Berlin / Shrewsbury: Peter Lehmann Antipsychiatrieverlag 2018. Und in: Peter Lehmann & Peter Stastny (Hg.): »Statt Psychiatrie 2«, Printausgabe, ISBN 978-3-925931-38-3, Berlin / Eugene / Shrewsbury: Peter Lehmann Antipsychiatrieverlag 2007, S. 358-368 [Information zum Buch siehe http://www.antipsychiatrieverlag.de/sp.htm].

Aderhold Ahern Alakare Baker Bartmann Beier Boevink

Bräunling Bruckmann Bucalo Carr Coldham Davar

DiGiacomo Dollwet Dumont Epstein Escher Gottstein

Hansen Hardy Hartmann Hausotter Herrick

Holmes Hughes Itten Jesperson Klafki

Krücke Lehmann Levine Maio

May Mead Millett Mitchell-Brody

Peter Stastny
Peter Lehmann (eds.)

Alternatives
Beyond Psychiatry

Preface by Robert Whitaker

(Ex-)users and survivors of psychiatry, therapists, psychiatrists, social scientists, lawyers and relatives report about their alternative work, their objectives and successes, their individual and collective experiences. The book highlights alternatives beyond psychiatry, current possibilities of self-help for individuals experiencing madness, and strategies toward implementing humane treatment.

These are the main questions addressed by the 61 authors from all continents:
- What helps me if I go mad?
- How can I find trustworthy help for a relative or a friend in need?
- How can I protect myself from coercive treatment?
- As a family member or friend, how can I help?
- What should I do if I can no longer bear to work in the mental health field?
- What are the alternatives to psychiatry?
- How can I get involved in creating alternatives?
- Assuming psychiatry would be abolished, what do you propose instead?

Oaks   Rippmann   Romme   Rufer   Sartori   Schützendorf   Seikkula

Solomun   Stastny   Stevenson   Taylor   Thomas   Wallcraft

Webb   Wehde   Welsch   Yasmeen   Ziegler   Zingler