

Section on Person-centered Public Health

## The service user as a person in health care—service users organising for self empowerment

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### Introduction

In 2009, we are discussing how to return to psychiatric patients their right to be treated as a person. The fact that we are having these events is an acceptance that there has been a problem in treating patients as people, as full citizens. In all societies there are specific laws and practices which exclude people thought to be mad or mentally ill, and medicine and law have worked together to achieve this exclusion. I am writing here as a person who became a mental patient in 1972 and received a PhD in 2002 through study of the mental health system and patients' perspectives.

### Loss of personhood in psychiatric healthcare—the history

The treatment of madness in previous centuries has rarely been humane or democratic:

*"They called me mad, and I called them mad, and damn them, they outvoted me"* Nathaniel Lee, Restoration poet on being committed to Bethlem in the 17th century [1].

Law and science in the 19th century was intended to offer justice and better health-care for the 'mad'. There was an awareness that people could be arbitrarily labelled as lunatics and their liberty and property unfairly taken from them. The Lunacy Acts in England and other countries were aimed to make loss of freedom less arbitrary. However, this did not improve the way that the mad were treated, or the conditions in the madhouses.

Science and law did not liberate the 'mad'. It provided an objective justification for isolating those deemed to be 'mad' from the rest of society—usually permanently. There was little conception that people might recover, and little distinction was made between permanent conditions of brain damage or learning disabilities and problems that might have been temporary.

Theories of madness set out a depressing prognosis for 'madness' which reinforced the role of doctors. An early 19th century medical journal [2, p. 149–150] states: "Insanity is purely a disease of the brain. The physician is now the responsible guardian of the lunatic and must ever remain so".

Lord Shaftesbury, an English aristocrat and member of parliament, dedicated his life to trying to help the poor. He was instrumental in the Lunacy Act of 1845. He spoke of the way that people deemed to be mad lose their personhood:

*"What an awful condition that of a lunatic! His words are generally disbelieved... . We know him to be insane, at least we are told that he is so, and we place ourselves on guard—that is, we give to every word, look, gesture a value and meaning which... it would never bear in ordinary life. Thus, we too readily get him in, and too sluggishly get him out, and yet what a destiny!"* [1].

In the 1990s, Shaftesbury's words are echoed in an article by service users:

*"Typically, on admission to a psychiatric ward, you are interviewed by a doctor. Many people expect this to be an opportunity to tell all that is troubling them to an expert who will help. But much of the interview is ... baffling. 'Count backwards from 100 in sevens' 'Do you believe your thoughts are being controlled?' There appears to be no space to say on your own terms and in your own words, just what are the difficulties that have reduced you to this situation."* [3].

## Reformers and allies in the 20th century

Many reformers have addressed the de-humanising effect of psychiatry on the person. In the USA, Erving Goffman wrote about institutionalisation and stigma, Thomas Szasz argued against the inhumanity of forced treatment, Peter Breggin wrote about the damaging effects of treatments, Phyllis Chessler discussed women's position in psychiatry given patriarchal assumptions about 'normality'. In the UK, R.D. Laing called for patients' experience to be the central focus and Suman Fernando wrote about the Western imperialist assumptions of psychiatry.

## Forced treatment

In the 20th century, psychiatric patients and former patients began to set up self help and campaigning groups in the USA, UK, and many parts of Europe. Early groups were small, vocal and angry, sensing their lack of power and the unwillingness of society or professionals to take them seriously. Many wanted psychiatry abolished, and were against medication and ECT because of their damaging effects. It was only when this movement gained strength and numbers (with the support of non-patient allies) that it was possible to refute the assumption that we could never be full members of society or participate in philosophical, political and scientific debates about mental illness.

Judi Chamberlin in the USA wrote an influential book about her own recovery and about how survivors of psychiatry were organising to raise their consciousness and help each other:

*"As [ex-patient] groups become more visible they recruit more members. This occurs because ex-patient groups speak to a truth of the patient-hood experience: that people's anger and frustration are real and valid, and that only by speaking out can individuals who have been harmed by the entrenched power of psychiatry mount a challenge against it" [4, p. 323–336].*

## Post-psychiatry

UK Psychiatrists Thomas and Bracken [5] argue for psychiatry to abandon its grandiose modernist assumptions that it had, or was about to discover, the explanation of and answer to mental illness.

They propose a more equal place for psychiatry among other professions, such as social work and psychology. They argue its concern should be good mental health care, not control, coercion and social exclusion, and for real partnership between doctors and patients. They call for an end to pharmaceutical company funding of research.

## The service user/survivor movement in the 21st century

British journalist, Jeremy Laurance [6] describes how patients are reclaiming their personhood:

*"In Britain, the growth of the users movement over the past decade is the ... most striking development in the mental health services. A plethora of groups representing different user interests have sprung up ... the organisations are demanding the right for mentally ill people to take charge of their own lives and, wherever possible, their treatment. 'Preserving independence and wresting control from the professionals are key themes ... non-medical alternatives ... such as crisis houses are in vogue.'"*

My report [7] showed that there is a shared agenda among service users in mental health:

*"Although service users/survivors are a diverse group, the On Our Own Terms report found important shared issues. A key shared issue is the right to be an individual and to have services that fit the person, not the label."*

Key elements in the common agenda I found include:

- Staff need to be more empathic and supportive
- Acute services should be drastically improved, perhaps with the help of advance directives
- Doctors should address life issues, not automatically prescribe medication
- ECT should be banned or at least more strictly regulated
- There should be more emphasis on prevention and non-medical alternatives, such as safe houses

With regard to psychiatric and mental health research, service users want to be involved in setting research agendas and to be fully involved in how research is conducted, analysed and disseminated [8].

## **Diagnosis and assessment—a service user perspective**

Based on my life and work experience these are views commonly expressed by patients and service users:

- Nosological diagnoses do not help us much. They are for classification and resource allocation. We need comprehensive or integrative person-centered diagnosis where we are enabled to tell our stories in our own way and in our own time.
- Assessment of needs can be done in full partnership with the person and their family and/or friends who will be part of their support system.
- Real partnership requires real changes in power dynamics, law and medical training.

## **References**

1. Porter R. *The Faber Book of Madness*. London: Faber; 1991.
2. Johnstone L. *Users and abusers of psychiatry: a critical look at psychiatric practice*. 2nd ed. London: Routledge; 2000.
3. Rose D, Campbell P, Neeter A. Community care: users' perspectives. In: Weller M, Muijen M, editors. *Dimensions of community mental health care*. London: W.B. Saunders; 1993. p. 320–1.
4. Chamberlin J. 'The Ex-Patients' Movement'. *Journal of Mind and Behaviour* 1990 Summer;11(3):323–36.
5. Bracken P, Thomas P. *Postpsychiatry: mental health in a postmodern world*. Oxford: Oxford University Press; 2005.
6. Laurance J. *Pure madness*. London: Routledge; 2003.
7. Wallcraft J. *On our own terms*. Sainsbury Centre for Mental Health; 2003.
8. Wallcraft J, Schrank B, Amering M, editors. *Handbook of service user involvement in mental health research*. Chichester: Wiley-Blackwell; 2009.