

# Service users, authority, power and protest: A call for renewed activism

Richard Lakeman and colleagues argue that there has been an explosion of roles for service users in mental health services in recent years. One consequence has been the emergence of a hierarchy among users, with some attaining 'celebrity status'. But the service user movement grew from protest and there continues to be a need for service users and others with an interest in promoting mental health to be activists, the authors conclude

## From the seeds of protest

The 'service user movement' is commonly understood to have its inception during the 1960s, a period which saw unprecedented interest in and collective action to secure human rights and equality for various groups. From within psychiatry, David Cooper, Ronald Laing, Thomas Szasz and Franco Basaglia, among others, questioned the way in which psychiatry was practised and some experimented with alternative approaches. From outside, scholars such as Michel Foucault and Erving Goffman assisted in mounting and popularising a critique of institutional psychiatry. The anti-psychiatry movement and other human rights movements of the time served as catalysts for the 'survivor' and 'service user' movements in the 1970s and 1980s. These movements shared an interest in protesting human rights abuses perpetrated by psychiatry, securing reform and advocating a radical rethink of the way psychiatry conceived of problems and treated people.

A social movement is a loosely bound collection of individuals, organisations and groups which share basic assumptions about a problem and co-participate in a range of projects designed to address these problems (Crossley 2002). The service user movement has shared not only some of the radical ideas of anti-psychiatry but a history of active protest. According to Coleman (1996) the roots of the service user movement go back as far as 1620 with the first recorded protest campaign by service users at the Bethlem hospital in London: 'The user movement started 376 years ago in this country when a petition was sent to the House of Lords from the poor distracted people of Bethlem, people who had been incarcerated by the system. They complained about physical restraints and treatments, about having to perform for their allowances for food, about their environment and poor food generally.'

Protest and resistance has been a response of individuals for as long as others have imposed their treatments on

## keywords

- > patients: empowerment
- > patients: attitudes and perceptions
- > self help groups

These keywords are based on the subject headings from the British Nursing Index.





human rights

equality

UNFAIR

collective voice

Sarah Perkins

them. However, the sustained criticism of the way public psychiatry has been practised and the collective protest by people who have had first-hand experience of services is a relatively new phenomenon. Campbell (2006) estimates that in the UK the number of independent user groups has increased from 50 in 1990 to 600 in 2005. This has been buoyed by the rise of 'consumerism' and calls for participation across public services generally. Service users now have an unprecedented collective voice and opportunities to represent their individual and collective view points in many forums.

Psychiatric reform has largely been a consequence of protest and lobbying. Foucault (1965) reminds us that the invention of madness as disease and the rise of psychiatric authority were consequences of lobbying on behalf of the medical establishment, who at the time had no explanatory theories or humane treatments to justify their involvement or authority. Much of the significant change in the care and treatment of those labelled mentally ill has been precipitated by protest from within psychiatry or more often from protest or public enquiry from without. The most significant and now taken for granted improvements in treatment and care were hard fought for and often resisted by the psychiatric industry – for example, the concept of 'least restrictive' treatment which now underpins mental health legislation in most countries, the removal of homosexuality from the diagnostic manual, and even the involvement of service users in any role other than patient (Rissmiller and Rissmiller 2006). Most western countries can proudly point to huge improvements in the care and treatment of people labelled mentally ill and increased legislated protection of people's rights. However, the continued use of coercion, forced treatment and incarceration of people labelled mentally ill; the lack of publicly-funded treatment or care alternatives to biomedical approaches to distress; and the over representation of those diagnosed with mental illness in almost every index of deprivation and

disadvantage suggest the need for sustained critique and continued pressure.

Hopton (2006) suggests that there is still a role for a 'critical psychiatry'. This movement aims to be less radical, less adversarial and less interested in challenging the underlying assumptions of psychiatry than anti-psychiatry. As an intellectual movement it involves using research findings to challenge demands for more coercion and highlights the limitations of evidence-based practice. According to Blazer (2005), anti-psychiatry contributed to the demise of social psychiatry and the emergence of a more scientific and medicalised view of distress. Social models of psychiatric distress were seen as a failure and alternative treatment models without an empirical base. Ironically, the fact that there are tens of millions of tardive dyskinesia victims (Breggin 1994) has rarely been seen as a failure of medicalised psychiatry. Despite scandals about newer antipsychotics causing diabetes and foreshortening life, and broad concerns about the medicalisation of everyday life, the view of mental distress as a genetic-biological aberration readily controlled if not cured by drugs, or some bio-genetic tweak, is more dominant now than at any other time in history. These taken-for-granted assumptions about bio-medical causation have been comprehensively and articulately critiqued and found wanting, the practices arising found damaging, and reasonable alternatives proposed (See for example, Read *et al* 2004). However, sound argument in itself is insufficient to shift the dominant discourse, institutionalised practice or counter the propaganda promulgated by those who profit from the status quo. Protest, particularly the weight of the consumer/service user voices, may well be necessary catalysts for change.

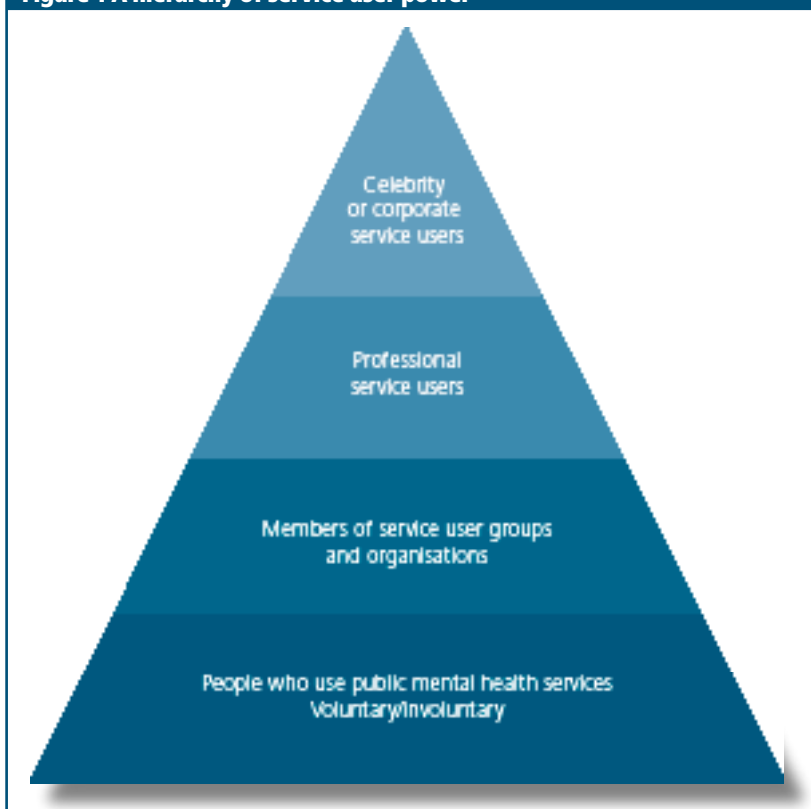
Despite a brief flirtation with the idea of bio-psycho-social health in the 1980s (Pilgrim 2002), the psychiatric emphasis in practice has become decidedly 'bio', and hypotheses about the biological causation of mental distress are treated as facts. Academics might talk 'stress-vulnerability diathesis models', but practitioners give out drugs. At the same time as this hegemony of ideas and practice has become entrenched, service users have assumed new roles (often remunerated) within the mental health service industry. This involvement is generally contingent on accepting distress as illness and acquiescing to the authority and expertise of psychiatry. It is a sad irony of service user involvement in the past 15 years, that some are well fed and have secured a seat around the mental health services table, but vast numbers go hungry (quite literally).

The response to the scandal of homelessness and poverty is too often a diagnosis of mental illness and an injectable atypical 'antipsychotic' (valued at more than the average pension) rather than assisting with basic needs or addressing the social and structural issues that lead to poverty. The position of those who use mental health services in society has deteriorated (Campbell 2001) and despite the apparent improvements in biomedical treatment, people diagnosed with schizophrenia today are twenty times more likely to die by suicide than those diagnosed 100 years ago (Healy *et al* 2006, Seeman 2007).

#### The hierarchy of authority and power

We propose that service users may be considered on a hierarchy of authority. At the bottom of this hierarchy are the vast majority of people who can make the most legitimate claim to the title 'service user', but they invariably have the least authority. Some actively seek and engage with mental health or psychiatric services in a negotiated partnership, but many are legally coerced to receive treatments that

**Figure 1 A hierarchy of service user power**



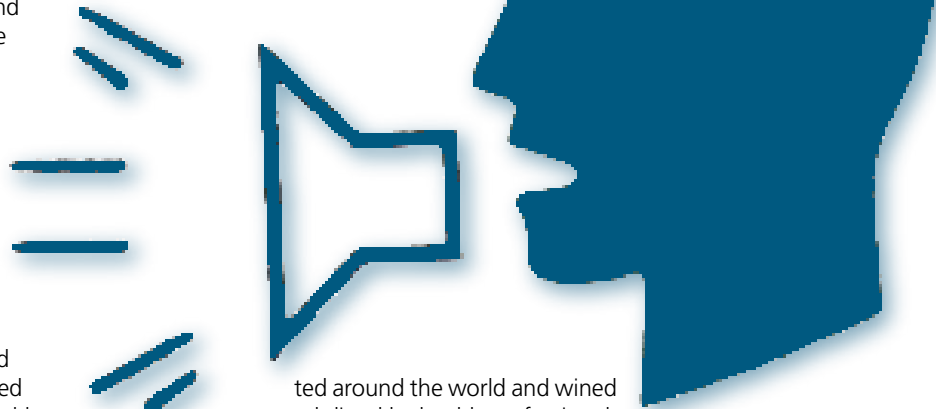
they object to, for problems that they don't construe as illness. Their authority is undermined by judgements of diminished decision-making capacity.

Service users at this level are heterogeneous and no-one can claim to represent their diversity of views and experiences. Some people with a history of some kind of service use may band together with others in the form of service user groups for a variety of reasons such as self help, camaraderie, or to lobby for service improvement. Sometimes the lines are blurred between being or having been a service user or having some kind of experience of mental illness. The authority of these groups often arises from some kind of claim to represent service users generally or particular sub-groups.

The professional service user is a relatively new role and might include those who invest considerable unpaid labour in service user groups, but also may be employed directly or contracted by institutions such as mental health services or education providers to perform particular services. These people need to have some commitment to the ethos, legitimacy and authority of the employing organisation which extends some of its authority to the employee, and the employee enhances the legitimacy of the organisation. For example, in being involved in recruitment and interviewing staff the organisation grants some limited authority to a service user to hire health professionals and in return may make a claim that the organisation cares about and actively involves service users. However, the organisation carefully moderates authority. For example, it would be a rare organisation that would tolerate a professional service user advising a person to not take their medication, to not disclose what is on their mind to health professionals in order to secure leave or discharge, or to maintain ordinary friendship with people within the service. Ironically the 'expertise by experience' that the service user might claim, may well have been the psycho-noxious effects of being secluded, forcibly medicated, coerced into receiving electroconvulsive therapy, or being patronised by staff, but the organisation rarely (if ever) extends any authority to the professional service user to actively intervene in these issues.

At the top of the hierarchy are people who might be called celebrity or corporate service users. These people are not constrained to the same degree as the professional service user bound to an organisation. They are often charismatic and highly articulate people who claim legitimacy through some prior involvement with mental health services or claim of illness. The more noxious the experience, for example being incarcerated, or more dramatic the story, for example of psychosis or suicide attempts, the greater the perceived legitimacy. Once these credentials are established they do not need to be renewed and, indeed, people often provide an account of recovery, transcending the need for mental health services or overcoming adversity. They typically project remarkable charisma, confidence, and talents.

The differences in lifestyle between those current service users compulsorily detained, forcibly medicated and with insufficient income to fuel a tobacco habit, and the celebrity service user could not be more stark. Some become corporate entities and demand large fees for appearances which are often augmented by book, CD and other product sales. They may enjoy a relatively lavish lifestyle being jet-



ted around the world and wined and dined by health professionals at their drug company-sponsored conferences. We have no argument that these people might influence health professionals towards more humanistic care. However, they pose no real challenge to the legitimacy or authority of psychiatric institutions, and health professionals can smugly congratulate themselves on their liberal open attitudes to service user involvement while carrying on business as usual. The more successful celebrities will be those who concur with a medical view of illness rather than seriously challenging prevailing views or practice. The authority of the celebrity often extends well beyond their knowledge, expertise or experience.

#### **A parallel process within psychiatry**

The stratification of authority, power and wealth that characterises the service user movement (or industry members) reflects a parallel process in psychiatry. The modern psychiatric industry has attracted or elevated celebrity spokespeople, figure heads and gurus, as have the many schools of psychotherapy. These people are often revered by their followers and their work and utterances treated as sacred. This may be necessary as much of psychiatric knowledge is knowledge by authority, that is truth is declared rather than discovered. In a similar way organisations may come to take on an oracle-like status (the National Institute for Clinical Evidence in the UK or the American Psychiatric Association in the US) whereby people uncritically accept whatever the organisation espouses.

At a more local level health services vest a huge amount of power and authority in psychiatry. Psychiatrists are ascribed expertise in all manner of things that go beyond their training, education or lived experience. A psychiatrist may have limited experience in psychotherapy but few challenge their legitimacy to comment on it or practice it. For some, poverty and the struggles of everyday people are an academic abstraction but rarely is their authority to advise poor service users how to live their lives challenged. Further down the psychiatric hierarchy we might include allied health professionals, nurses, professional service users, families and carers and finally, at the bottom of the hierarchy, the ordinary service user. These people are presumed to have the least 'insight' into their problems, whereas, all above are presumed to have more.

*'It is our contention that this hierarchical structure of knowledge and authority in the service user movement and psychiatric industry is problematic'*

### Towards renewed activism

It is our contention that this hierarchical structure of knowledge and authority in the service user movement and psychiatric industry is problematic. It serves to maintain the status quo and to subjugate ordinary service users. Particularly problematic is the automatic extension of authority and presumed expertise that comes with elevation in the hierarchy. We contend that the experience of service usage might provide a particular type of expertise but it should not be used to lend legitimacy to any claim. All people have particular personal and professional interests and these should be acknowledged. We fear that the service user mantle is sometimes used to endorse products, reinforce psychiatric authority, promote personal interests and career aspirations, but the lot of the service user at the bottom of the hierarchy is not manifestly improved as a result.

Rissmiller and Rissmiller (2006) contend that the antipsychiatry movement evolved into mental health consumerism which has achieved many gains largely because it is less radical and confrontational. Nevertheless, there continues to be a need for a radical edge to the service user movement – a willingness to challenge authority, seek social and structural change and to protest. With the development of service-led models of self-help and care (for example, club houses, GROW, self help groups or the Hearing Voices Network) there is a need to be mindful of not replicating the hierarchical power and authority structures of mainstream institutions. People who are unwittingly elevated or court celebrity status have some particular responsibilities. They must be mindful of the social and structural forces that impact on and subjugate people. They must take care not to collude in over-simplifying the mental health problems or solutions of others. They must not lose interest in or abandon users of public mental health services in the development of complementary or alternative care systems.

Professional service users may have particularly difficult roles in terms of 'not biting the hand that feeds or provides treatment'. They may, quite reasonably, want to minimise conflict and acquiesce to the seemingly reasonable demands of health professional colleagues. They risk being isolated, manipulated and assimilated. Some might best realise a protest agenda outside of their mainstream roles through affiliation with other groups, or choose their local battles very carefully. All must be mindful of the protest routes of the service user movement and who or what they represent.

Stickley (2006) argues that service users have attempted to ascend the dominant discourse, in essence failing to step

outside it. They might achieve greater social change through independent user or emancipatory projects. Barker and Buchanan-Barker (2003) warn service users of the danger of being assimilated into the very services they are attempting to change. People may be caste into roles that allow little more than tweaking local practice and disallow more radical critique or any challenge to psychiatric authority.

### Conclusion

We believe that the service user movement needs to return to its roots, its *raison d'être*: a collective voice demanding social transformation steeped in human rights and equality. We need to move away from the intellectualisation of the 'problems of living' and address basic human needs such as acceptance, belonging and autonomy which many service users are denied. It is a moral obligation to maintain the protest movement, to seek social justice for those who have or continue to suffer due to psychiatric treatment, and to advocate for alternatives and improved care.

Finally, all those with an interest in promoting mental health ought to question and sometimes challenge claims to authority and expertise. Rampton and Stauber (2002) suggest that activism is not just a civic duty but a path to enlightenment. The seeds of the service user movement were sown at a time when many groups were challenging the institutions of society and there was a heady optimism that a better way to live might be realised. This level of idealism and optimism may have been replaced with materialism and consumerism, but many of the issues relating to justice, inequality, and rights abuses of people treated as mentally ill remain outstanding.

Addressing these issues involves questioning and challenging those individuals and institutions that claim to know what is best for other people. The over-emphasis on the biological basis of mental distress to the exclusion of consideration of social and structural issues needs to be challenged, as do continued coercive practices based on authority. We commend service users and allies to continue being activists ■

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### References

- Barker P, Buchanan-Barker P (2003) Death by assimilation. *Asylum*. 13, 3, 10-12.
- Blazer DG (2005) *The Age of Melancholy: 'Major Depression' and its Social Origins*. Routledge, New York.
- Breggin PR (1994) *Toxic Psychiatry: Why Therapy, Empathy, and Love Must Replace the Drugs, Electroshock, and Biochemical Theories of the 'New Psychiatry'*. London, St Martin's Press.
- Campbell P (2001) The role of users of psychiatric services in service development — influence not power. *Psychiatric Bulletin*. 25, 3, 87-88.
- Campbell P (2006) Changing the mental health system — a survivor's view. *Journal of Psychiatric and Mental Health Nursing*. 13, 5, 578-580.
- Coleman R (1996) The construction of psychiatric authority. *Asylum: The Magazine For Democratic Psychiatry*. 10, 1, 11-15.
- Crossley N (2002) Mental health, resistance and social movements: the collective-confrontational dimension. *Health Education Journal*. 61, 2, 138-152.
- Foucault M (1965) *Madness and Civilization: A History of Insanity in the Age of Reason*. New York, Random House.
- Healy D, Harris M, Tranter R, Gutting P, Austin R, Jones-Edwards G, Roberts AP (2006) Lifetime suicide rates in treated schizophrenia: 1875-1924 and 1994-1998 cohorts compared. *British Journal of Psychiatry*. 188, 3, 223-228.
- Hopton J (2006) The future of critical psychiatry. *Critical Social Policy*. 26, 1, 57-73.
- Pilgrim D (2002) The biopsychosocial model in Anglo-American psychiatry: Past, present and future? *Journal of Mental Health*. 11, 6, 585-594.
- Rampton S, Stauber J (2002) *Trust Us, We're Experts: How Industry Manipulates Science and Gambles with Your Future*. New York, Tarcher/Putnam.
- Read J, Mosher LR, Bentall RP (Eds) (2004) *Models of Madness: Psychological, social and biological approaches to schizophrenia*. New York, Routledge.
- Rissmiller DJ, Rissmiller JH (2006) Evolution of the antipsychiatry movement into mental health consumerism. *Psychiatric Services*. 57, 6, 863-866.
- Seeman MV (2007) An Outcome measure in schizophrenia: mortality. *Canadian Journal of Psychiatry*. 52, 1, 55-60.
- Stickley T (2006) Should service user involvement be consigned to history? A critical realist perspective. *Journal of Psychiatric and Mental Health Nursing*. 13, 5, 570-577.