

Struggling for subversion

Service user movements and limits to the impact of client led accountability

PROFESSOR BRIAN BROWN BROWN@BROWN.UK.COM
Professor of Health Communication, De Montfort University

SALLY BAKER
Research fellow, School of Social Sciences, Bangor University

CHARLEY BAKER
Lecturer in Mental Health, The University of Nottingham

ABSTRACT

Since the invention of the service user as a medico-political category, service user involvement has been advocated by policymakers and researchers as a way of empowering clients and ensuring service responsiveness and accountability in mental health care in the UK. However, our experience of involvement in this field over the past three decades suggests that these initiatives may have limited emancipatory impact. Service providers may be adept at ensuring that only certain kinds of service user voices are legitimated and heard, and more critical transgressive voices are sidelined. Moreover, service user involvement has implications which are seldom appreciated, such as the opportunities for patronage, co-optation of tame users and nepotism within the service user organizations themselves. The experiences we relate here suggest that, as presently constituted, service user involvement and empowerment does not necessarily make users powerful. Indeed, without a careful reconsideration of the present arrangements for service user representation, it may well consolidate notions of passivity, medical models of human distress and deflect the liberatory potential of transgression. The implicit and sometimes explicit stipulations of what it means to be a 'good patient' attenuate the potential for meaningful change and obscure the exercise of power within the mental health system.

Struggling for subversion: Service user movements and limits to the impact of client led accountability

Transgression is an action which involves the limit... Limit and transgression depend on each other for whatever density of being they possess: a limit could not exist if it were absolutely uncrossable and, reciprocally, transgression would be pointless if it merely crossed a limit composed of illusion and shadows... . Transgression, then, is not related to the limit as black to white, the prohibited to the lawful, the outside to the inside... . Perhaps it is like a flash of lightning in the night which, from the beginning of time, gives a dense and black intensity to the night it denies, which lights up the night from the inside, from top to bottom, and yet owes to the dark the stark clarity of its manifestation, its harrowing and poised singularity. (Foucault, 1977: 33, 34, 35)

Introduction: user involvement, empowerment and reform

In the United Kingdom, the previous Labour government's policy – continued by the Coalition from mid-2010 – regarding health and social welfare services has assigned a pivotal role to the notion of the 'service user'. Service users – previously referred to by terms such as patient or client – are now 'consulted', 'involved', 'engaged with' and 'empowered'. Whilst involving recipients of services in decisions affecting their services and treatment promises 'empowerment', the practice for service users has often been profoundly disempowering: 'When the calls for participation come from the providers, the result is often a diluted experience on the terms of those in power' (Dearden-Phillips and Fountain, 2005: 200).

As Georges Bataille (1962) notes in his work on transgression, there is a tendency for rules to rise more acutely to prominence, and to be more assiduously enforced during moments of transgression, 'for it is harder to limit a disturbance already begun' (Bataille, 1962: 65). In this light, we would expect that where service user involvement shows the most potential to make a difference to mental health care systems, it might be most diligently policed and constrained. In this paper therefore we critically examine the transgressive potential of a series of examples of service user involvement experiences. We have been participant observers in mental health care in one form or another as clinicians, scholars, and sometimes as recipients of care, for a quarter of a century and our experience reflects our engagement with a diverse range of institutions and styles of delivery, including hospital, community and primary care. In relation to the recently coined concept of the service user, we are particularly interested in the frequent use of discourses of 'empowerment' in mental health services. The term, like 'service user involvement', seems to be so widespread as to have largely escaped scrutiny. Aujoulat and colleagues (Aujoulat, d'Hoore and Deccache, 2007) note that one

important aspect of the use of the term empowerment has been as an alternative to the older notion of 'compliance'. Whilst the more traditional compliance-oriented approach to health care saw 'good patients' acting as the passive recipients of medical decisions and treatments, the empowerment-oriented approach 'views patients as being responsible for their choices and the consequences of their choices' (Aujoulat et al., 2007: 13). Moreover, in contemporary usage, whilst the term is rarely explicitly defined, it is often geared towards some anticipated outcome, such as 'self-management' or 'self-efficacy' – the implication being that active involvement in care levels an inherently uneven playing field somewhat, under the guise of empowerment, which implies that the empowered patient is also a good patient – one whose condition improves and whose demands on the service diminish.

An empowered service user is certainly not necessarily a transgressive one, in the sense of transgression elaborated by Foucault (1977). Similarly, as Masterson and Owen (2006) argue, the term empowerment is used in health and social care with little reference to any of the sociological theories of power. As a consequence, those who are empowered as a result of changes in service delivery seldom turn out to have become powerful. Rather, it most often means they are *held responsible* for their state of health. Empowerment then, rather than facilitating transgression and transformation, is as Bataille (1962: 65) reminds us often as much subject to rules as the background state of compliance itself.

As even the most cursory glance at policy in health and social care over the last 15 or so years in the UK will indicate, service user involvement has been encouraged through many policy channels. The UK's *NHS Plan* (Department of Health, 2000) proposed that trusts should ensure that patients were able to comment on the services through surveys and other forums. Trusts were enjoined to ensure that patients were represented at board level, as well as being entitled to more information on their care and be supported by Patient Advocacy and Liaison Services. In mental health care, the Department of Health's *National Service Framework for Mental Health* (Department of Health, 1999: 4) enjoins providers to 'involve service users and their carers in planning and delivery of care'. Moreover:

When service users are involved in agreeing and reviewing the plan, the quality of care improves, and their satisfaction with services increases. They want to be involved, but commonly feel excluded. The quality of the relationship between patient and professional in psychological therapies can make as much as a 25% difference in outcome. (Department of Health, 1999: 45)

More recently, Harry Cayton, National Director of Patients and the Public at the Department of Health, was quoted in the inaugural LINKS Bulletin:

Patients, carers and users of services are the real experts in the care they need and want, their input is therefore essential if services are to be tailored to their needs, to create a user led health and social care system. (Cayton, 2007: 2)

Thus is the case framed persuasively. For policymakers and officials, the involvement of service users leads to better services, more appropriately geared to health needs. Furthermore, it leads to a notion which was increasingly notable in New Labour policy, and even more so in the age of austerity and cuts under the Coalition Government with its talk of 'Big Society' – that of citizens becoming 'responsibilized' (Brown and Baker, 2012). This process of assigning responsibilities to citizens played an important role in New Labour's view of the modern world and indeed is at the heart of recent Coalition government policy. 'Citizens are the bearers of responsibilities as well as rights. Such responsibilities are substantial and wide-ranging. At their core is the responsibility to produce the conditions of one's own independence' (Clarke, 2005: 451). Certainly, the responsible service user is enjoined to strive to regain their health and economic independence. But there is a further process at work. The active citizen, the expert patient or the service user representative have been co-opted to make a money-saving governmental agenda more legitimate. Madness then in this new regime is not a transgressive state, but the ideal good patient is someone who accumulates new responsibilities, for engagement with treatment programmes and prudent participation in service users' groups and consultation exercises. Unlike bell hooks's formulation of knowledge and education as being a 'practice of freedom' these new kinds of self-knowledge and self-discipline on the part of service users have not 'taught them to transgress' (hooks, 1994).

Aligned with hooks's concerns, the service users' movement is a source of constraint rather than liberation. Croft and Beresford (1995) highlight the risks of service providers co-opting users' views to legitimate their own agenda. Cowden and Singh (2007) argue that instead of enabling the delivery of high quality services that reflect the interest of present and future service users, the mantra of 'service user' has simply resulted in the further commodification of human needs and welfare. Moreover, as we shall argue, it is a commodity vital to shoring up a variety of retractions in services.

Joining the professionals: service users at work

In our longstanding relationships with mental health service users and statutory agencies, we have seen many incidents which suggest that the notion of ‘service user involvement’ may be reformulated by enterprising service providers to deflect any subversive questioning of the existing structure of care. It can be used to legitimate withdrawals of provision, or to maintain clients in the role of ‘good patient’ in the face of reduced standards of service. Even more creatively, service user involvement can be used to convince regulatory authorities that all is well in troubled services dogged by controversy and complaint. Most of our examples come from services in North Wales, as it is these which have yielded most of our firsthand experience, but similar accounts are increasingly emerging from regions in England. As Cowden and Singh have noted, the last decade has seen a burgeoning of ‘professional service users’, both at local and national level, who are ‘consulted’, enabling service providers to maintain that services are being developed and delivered with service user consultation. As Cowden and Singh (2007) describe, many of these ‘professional service users’ have indeed officially become ‘consultants’ and some have, in the spirit of new entrepreneurship, been able to set up agencies offering ‘training’ and ‘consultancy’. The term ‘consultant’ is clearly more attractive to users and providers than terms like ‘activist’, ‘campaigner’ or ‘survivor’. More recently, and more encouragingly, Peer Support Workers have been developed, trained and employed by NHS trusts (Bassett et al., 2010). Yet even this positive move continues to demarcate service users as different from ‘legitimate staff’ in many respects – though Bassett *et al* do mention the role of non-Peer Support Worker staff who are also service users.

The language of service user-hood is drawn from business culture, a notion supported by other terms such as ‘representatives’ and ‘committee members’. Indeed, this linguistic colonization from occupational discourse means that that senior service user representatives are referred to as ‘chairmen’ or ‘chairs’. They may be ‘directors’ of service user groups. Most of the people that we have encountered in such roles seem to have achieved their position through being well-connected within relatively small user networks. This nepotism and the reliance on funding from health care trusts, charitable or statutory funding means that service user organizations are often closely aligned with the health care organizations that host them, thus echoing the careful regulation of transgression noted by Bataille – ‘no liberation here’ (Bataille, 1962: 65). As a corollary of this, it is possible that those who are included in the service user enclaves differ in their views and agendas from the wider population of those who use services. In North Wales we have been told by both clients and staff

that many of the service user representatives were often anything *but* representative of the views of the wider body of service users. Allegations of ‘they’re just giving jobs to their friends’ were common, as was the claim ‘if you disagree with them they just kick you out of the group’. One consultant psychiatrist told us angrily that in the seven years that the service user group had been in existence at the trust in which he worked, there had not been one democratic election or advertised post. This may also be responsible for the degree of alignment in opinion between the service providers and the service users themselves rather than a representation of the wider body of service users that adopts a manner more transgressive of medico-political orthodoxy. As hooks might have it, the process of involvement ‘teaches obedience’ (hooks, 1994).

The sphere of influence

In the North Wales area, like the rest of the UK, mental health service users are now supposedly consulted and involved in the delivery and planning of services. Yet even so, they are often only invited to give an opinion in certain domains. For example in one unit with which two of the authors (BB and SB) are familiar, there was a long-running controversy over the catering, and user representatives became embroiled in concerns over the palatability and temperature of the food that was served for the midday meal. Equally, service users became involved in matters pertaining to patient surroundings, such as the provision of a women-only day room, or matters of décor. They are not, in the areas we have studied and worked in, formally included in decisions on matters of policy or budget. Nor are they drawn into any debates on clinical judgement, such as the benefits or drawbacks of drug therapies, electroconvulsive therapy, restraint or isolation, or matters arising from the use of compulsory powers under the Mental Health Acts. As Foucault reminds us in *Preface to Transgression* (Foucault, 1977: 30), once we have become entrained in a particular discourse, we are limited in the kinds of consciousness we can entertain about the issue. Hence, there was thus little evidence of challenge or organized subversion of the *status quo*. The domains of activity where service users’ views are included are arguably somewhat peripheral to the major part of management activity or clinical work in the hospital settings. The preoccupation with consumer choices or day-to-day ward life means that the people most likely to be challenged by service users are catering or nursing staff, rather than medical staff or managers, and certainly not policymakers or politicians.

The active control of agendas, topics and definitions of involvement itself by staff is something we have witnessed many times. Some 20 years ago, one of the authors participated in an open ward meeting in

a teaching hospital that prided itself on consulting patients well before this was accepted policy. Virtually every patient on the ward made angry complaints about one abusive and threatening patient who was perceived to be receiving 'special treatment' because of alleged close relationships between her family and the medical staff. The ward manager shouted at the patients that they were not to comment about this matter and that was that, he wouldn't listen to such complaints. One patient observed that this was a strange sort of democracy and she was later told that she would not be welcome at any future patients' meetings. Such experiences as these feed our suspicion that service user involvement frequently offers a largely cosmetic solution to the problems of engaging stakeholders in the planning and delivery of services. The potential for transgression, as Bataille presciently noted, is hedged about with rules and regulations which limit its emancipatory impact. It is often not facilitated in a way that will yield substantive gains in the delivery of services and therapeutic interventions nor in effective positive risk taking or the enhancement of client wellbeing.

Of course, these kinds of limitations do not serve to invalidate the idea of service user involvement and do not necessarily suggest that these difficulties are experienced everywhere. Yet once the threads of despair and failure are tugged, the edifice of public service might unravel further than anyone can control. This particular event suggests that service user involvement can provide a stalking horse behind which more serious failures of service can be concealed.

As Makitalo and Saljo (2002) have argued, the public services are adroit at classifying their clients, and these categories serve a range of functions. The events we have observed suggest that the public services in this case are making decisions about where it is and where it is not appropriate to involve service users and the kinds of service user involvement which is considered legitimate. We have frequently noticed an informal classification of people into the kinds of service users whose views can be taken seriously and those whose views need not. Those whose opinions were listened to were not always those who used services the most widely, or those who could consult with the largest cross-sectional group, but those who played a complaisant role and were easiest to console, sometimes with as little as a tokenistic listening ear.

Closing off debate: user consultation and withdrawing facilities

The statements above are perhaps strong and contentious ones. Let us therefore illustrate them with some examples. In BB and SB's work in North Wales we were able to see how service providers themselves became increasingly adept at deploying the discourse of service user in-

volvement in order to achieve their own objectives, no matter how unpopular these were with the wider service user body. We are aware of two instances in two different regions of Wales of popular day centres being closed in the face of local protest. Both authorities involved claimed that 'service user consultation' had informed the closures. The story behind these events is interesting enough to warrant further discussion.

In both cases the service user groups were dominated by a small group of users who appointed one spokesperson. We were consistently told by other users that these spokespeople were not representative of the views of the wider group. Indeed, in one authority, one of these spokespeople had a poor relationship with many of the service users that he claimed to be representing and a number of people frankly expressed the opinion that he was simply relaying instructions from the hospital authorities. A meeting was organized with service users and 'management' to 'discuss' whether the day centre should remain open. One of the authors was present at this meeting. At one point the meeting descended into near chaos with angry service users shouting abuse at their 'rep' who was chairing the meeting, as well as at the one senior nurse and one manager who were present. One user then announced that he had 'discovered' that a consultant in the trust had been given a 'meritorious award' (presumably a performance related merit award) for organizing the closure of the day centre, and demanded to know if this was true. The service user representative in his capacity as chair told the manager that he didn't have to answer that if he didn't want to. The manager, naturally, declined to answer. The participant then repeated the question directly to the manager. He was told by the senior nurse that all questions had to go through the chairman, namely the service user representative. A number of those present angrily denounced the meeting as a farce and left. The manager then left stating that he could spare no more time. Shortly after, the day centre was closed and a hospital spokesperson was reported in the local press as saying that there had been extensive consultation with service users over this decision. The service user representative chairing this meeting subsequently achieved notoriety at a service user conference by saying that 'my job is to do what the NHS wants'.

A comparable process of categorizing service users into those who were and those who were not taken seriously occurred in the case of a different day centre administered by another health authority. Many people who were known to have spoken against the closure of the day centre in the local media were not receiving invitations to crucially important 'open' meetings. On one occasion, a minibus laid on by the service users' group to take the service users to a meeting regarding the future of the day centre failed to arrive at a prearranged pick up point to collect a particularly vocal service user who had defended the day centre

on local radio. Echoing what one of the authors had witnessed in the teaching hospital years ago, this service user was then told that she was no longer welcome at service user meetings. There was then an attempt to discharge her from outpatient care on the grounds that she could no longer be considered a 'vulnerable person'. She enlisted the help of a local politician at this point, who took up her many complaints and after an investigation by an external body, a number of them were upheld, including those pertaining to various abuses of process by some members of the service users' group. As part of his support for the day centre, this politician offered to attend a users' group meeting and many service users were keen for this to happen. He subsequently received an invitation to a meeting, but only on condition that a senior member of staff from the local social services was present too. The managers and staff of the local health and social services authorities seemed to wield a great deal of influence among the official representatives in this particular service users' group and were able effectively to manage service user reaction to the retractions in the services available.

These two cases are ones that BB and SB have experienced firsthand, and in the course of our involvement we were able to speak to many of the people involved and attend the meetings in question. We present them here because they show in detail the possibilities provided by processes for managing service user opinions, deflecting more transgressive views, and ensuring that any potentially problematic objections are sidelined. The subversion immanent in the notion of service user involvement is mitigated, marginalized and in some cases nullified in practice. The ingredients are the same in each case – a 'tame' user representative backed up by a small clique of selected service users, who are perceived to be doing the bidding of the service provider; service providers making unpopular decisions; dissenting voices among service users being extinguished, usually by their removal from the service user group.

Thus the permission to belong to a *formal* service user consultative group is often still informally in the hands of practitioners and managers. Their decisions as to whose voices to legitimate potentially compounds the social exclusion which is part of the experience of mental health care (Bertram and Stickley, 2005) and contributes to a process of dehumanization (Sayce, 2000). By not thinking of the more transgressive mental health service users in terms of their citizenship in the wider community, mental health practitioners condemn them to a marginalized, outcast social role, reinforcing the stigma attached to their status. The concerns some service users, as active citizens, have with public services are used effectively to disenfranchise them from participation in the process.

The two examples we have given thus involve the subversion of the opinions of clients and the denaturing of their self-identified needs,

and hopes for therapy, into the much more docile notion of 'service user consultation'. The legitimacy this grants the service providers serves to make the efforts of any challengers less likely to bear fruit. The sheer impenetrability of the procedures to anyone not in the clique of approved opinion renders the likelihood of significant policy change as a result of more subversively motivated service user involvement even lower.

Limits to the impact of client led accountability

Whilst we have focused on events and incidents in two relatively circumscribed geographical areas, there are growing indications that the problems we have identified are by no means isolated incidents. Much service user involvement seems to lack the original radicalism and to have toned down the subversive challenge to the idea of mental illness and the medical model of service provision that was present in earlier described users' and survivors' movements (Chamberlin, 1998a,b; Emerick, 1996; Everett, 1994). Within the North Wales region, all the service user representatives and service user consultants that we came into contact with subscribed to mainstream medical discourses regarding the existence of 'mental illness', its possible causes and ways of treating it – they were unacquainted with dissenting views. They were also remarkably uncritical of other present-day orthodoxies – we were told that 'mixed sex wards are bad' and that people who have been sexually abused 'feel dirty'. The person who commented on the deleterious effects of mixed sex wards became quite confused when she encountered a female service user who was firmly in favour of being cared for in a mixed sex environment – she had not even envisaged such a possibility.

We have even encountered service user representatives or consultants who were able loftily to invalidate the dissenting views of some of those that they were supposed to be representing 'because they are ill'. This represents a problem for more vulnerable, marginalized and transgressive service users, especially given the vigour and intransigence with which these dominant views were held by the more favoured service user representatives, which enabled the force of some people's criticisms to be discounted because of their 'illness'. Some service user representatives and consultants also showed considerable enthusiasm for using rather questionable 'knowledge' of 'mental illness' to explain and invalidate the motives or behaviour of other service users, in the manner of what Sumner (1990) calls an 'organized slander'. In sum, much of the service user involvement we have seen, and which we describe in this paper, was hierarchical, status ridden and undemocratic with little opportunity for problems to be addressed or egregious behaviour to be challenged. The service user representatives and consultants at times claimed the same

type of master status for themselves as patients that they found so offensive when it was claimed by mental health professionals on their behalf.

Yet power relationships were, and are, further confused by the fact that many of the service user representatives and consultants are dependent upon the services that they are supposed to be involved in developing and running, both for their personal wellbeing and for funding and facilities for the service user groups in which they are involved. This meant that there often seemed to be a rather uncomfortably cosy relationship between the various manifestations of service user groups and service providers, where the service provider was the dominant partner, especially where the service providers fund service user organizations. One service user group which ran the patient advocacy service for the North West Wales region produced leaflets and other literature advertising an 'independent advocacy service'. Yet we were told by the director of this advocacy service that 'we can't really pursue serious complaints against the mental health services because the Trust funds this service'.

In these most practical terms, it is therefore sometimes a struggle to be subversive, and there are often compelling reasons to be compliant and a good patient. This brings to the fore Bataille's (1962) reminder of how transgression itself is often rule governed and how the historical dominance of established structures will rapidly supervene over attempts to transgress. We also met a volunteer advocate who had resigned from a particular group when her line manager had told her not to support patients if they were making serious complaints. We had some indication of the human cost of this situation when the mother of a young man who had died while in the care of this trust said to us angrily after contacting the advocacy service for help, 'they were useless, they didn't want to know. Independent advocacy, they were terrified to face the hospital'. The presence of the advocacy service then seemed to be apt to create expectations which it was often unable or at least disinclined to fulfil.

Since these observations were made, the management of this particular trust has been extensively restructured and it is now led by a new senior team with a commitment to reform and transparency. This has proceeded in tandem with changes in the overall governance of public services in Wales, with consequent opportunities for improvement.

Transgressing away from user status and the idea of the good patient

Whilst we have described the situation of service users and their involvement as being limited in this article, it need not always be this way. Certainly, there are institutional forces at work which limit the potential for transgression or reframing the discourses, practices and kinds of as-

sistance proffered within the mental health services. Yet it is still possible for service user involvement to recapture some of the transformative potential that it exhibited a generation ago. One source of inspiration is the literature on transgression itself. As bell hooks reminds us, it is valuable to minimize the fear attached to novel or alternative ways of thinking and to engage in the ‘decolonization of ways of knowing’ (hooks, 2003: 3). Thus, it might be possible to conceive of service user spaces as ones where people are not merely taught the orthodoxies of mental disorder and service provision, but are enabled to think rigorously and critically, and to engage effectively, meaningfully and strategically in the design and delivery of services. In Foucault’s work, whilst dominant discourses are seen to shape the possibilities for consciousness, there remains an ethical imperative to push against these limits. Following Foucault in his *Revolutionary Action* (Foucault, 1971: 45), we can attempt to ‘change this ideology which is experienced through those dense institutional layers where it has been invested, crystallized, and reproduced’. The force of any transformational movement needs to ‘attack the relationships of power through the notions and institutions that function as their instruments, armature, and armor’. To do this requires ‘a kind of aggressive enquiry formulated, at least in part, by those who are being investigated’. Thus it would become possible for the knowledge garnered from the situation of service users to be situated within the official version of what service users want.

Until now, institutions have tended to define ‘user involvement’ through an essentially collaborative arrangement between themselves and groups of users who may be co-opted and professionalized so as to be good users, good patients and limit the transgressive or liberatory potential of user involvement initiatives. The selected users become even more passive in their relationship with the health care providers. Indeed, in one of the examples given above, the fact that the woman campaigning against the closure of a day centre was an effective advocate for the preservation of services and had succeeded in gaining access to local television and radio to protest about the proposed closure was used against her by the service provider. Her subversive activities had enabled them to define her as someone who was not ‘vulnerable’, so she was discharged from services. Despite the change in nomenclature from patient to service user the presumption of passivity remains intact (Neuberger and Tallis, 1999).

The role of the service user as a representative of a wider body of recipients and as a shaper of policy is as Cowden and Singh (2007) indicate, a peculiar position indeed. The commodification of welfare means that the customer may exercise choice, yet at the same time there is often little effective choice for users, other than the very services which give rise to grievance and dissatisfaction in the first place (Wilkinson, 2001). As

Leiberman notes, clients often ‘receive marginal, fragmented and inadequate services that hamper recovery’ (Leiberman, 2002: 338). Moreover, people’s experience as ‘service users’ in mental health may well involve coercion or compulsion, so redescribing this as somehow akin to consumerism draws attention away from the exercise of power involved. People who have often had the unhappiest experiences of services can often find themselves struggling on their own to subvert the structures of power within which they have been abused. For example, those who have experienced violence from staff in mental health care are apt to advocate major changes in the infrastructure of the mental health system itself (Kumar et al., 2001) of a kind which present day systems of user involvement are unlikely to achieve. These differences lead Beresford (2003) to suggest that we should consider user involvement critically, and be suspicious of a ‘monolithic approach’ to user involvement. Cowden and Singh (2007) argue that the whole consumerist idea of the ‘user’ falls apart when peoples’ positions as users of mental health services are explored, because many people are not using these services through choice.

The idea of service user involvement also presupposes that users will be involved for a period of time within the system. Indeed, service user careers may develop which culminate in their becoming consultants or advisers. This invites the question of whether their involvement is itself hindering recovery. Whilst Ramon and his colleagues (Ramon et al., 2007) note that a sense of control over one’s life is important in the recovery process, the experiences of frustration and marginality identified here might even have a *negative* impact on people’s chances of improvement. Alternatively, those who fully embrace the service user identity and participate in a complaisant and docile fashion in the various service user activities permitted by health care trusts are unlikely to gain the mastery and success experiences deemed helpful to recovery. Indeed, there are some suggestions in the literature that those who leave the services behind have better outcomes than those who remain involved (Cohen, 2003; Harding et al., 1987; Kelly and Gamble, 2005).

Through the examples presented here we have sought to problematize the notions of service user involvement and empowerment. An idea which might have seemed seductively radical and capable of transgressing the structures of conventional mental health care a generation ago has been rolled out on a nationwide scale in the UK, and despite hopeful reports, it seemed to us that something was blunting its potential to achieve effective change. This paper then is an attempt to show how this process of blunting might take place. Of course, it is based on a limited set of experiences but it signals the importance of investigating what user involvement means in practice and opening up to scrutiny the workings of user enclaves as they liaise with and are co-opted into

health authorities, boards and trusts, and have all but given up the struggle for subversion. It highlights the importance of critically examining the processes of 'empowerment' as they are practically implemented and entertaining the possibility that 'users' of mental health services are still in such powerless and vulnerable situations that they exert negligible force as citizens or consumers. Often they will indeed struggle to subvert the broader impress of power.

In more practical terms there are some initiatives and ideas which may yet bear fruit as a means of more fully representing service user interests in the design and delivery of services. The recent adoption of the Peer Support Worker role in several NHS trusts, whereby service users are formally employed, on equal terms with other clinical workers, may be one way of facilitating this necessary change and challenging the issues we have highlighted (Basset et al., 2010) – the long term impact of this model remains to be seen. Another possibility is presented by the notion of self management (Crepaz-Keay, 2010: 3), 'putting patients (service users) in direct control of managing their conditions'. This involves a transfer of focus from treating the client's condition to enabling people to live with it in the longer term. The focus does not have to be on a particular diagnosis but can involve a more practical concentration on how to respond to obstacles faced by the individual.

Perhaps just as importantly, we need forums where discussion of the limitations of existing models of service user involvement are not sidelined, marginalized and rejected. At present it is all but impossible to place papers which detail the abuses of the mental health care system against its users, or the shortcomings of existing patterns of involvement, in mainstream academic journals. Whether concerned with nursing, psychiatry or social policy, a small coterie of experts in service user research veto material which does not adhere to a relatively narrow party line. More challenging inquiries have now become instead the territory of investigative journalists with concealed cameras rather than researchers, service users or anyone seeking to place their discoveries in a meaningful theoretical framework.

Yet it is only by probing the possibility that the present model may be limited that we can genuinely move towards a situation where people experiencing mental health difficulties can be consulted and empowered in ways that do not simultaneously oppress them, and services can be reconstructed so as to place them and their needs at centre stage. As Bataille has noted, whilst many transgressions are rule bound, there may yet be the potential for 'transgression without limits' (Bataille, 1965: 65).

References

- Aujoulat, I., d'Hoore, W. and Deccache, A. (2007) 'Patient empowerment in theory and practice: Polysemy or cacophony?', *Patient Education and Counseling*. 66: 13–20.
- Basset, T. Faulkner, A. Repper, J. and Stamou, E. (2010) 'Lived Experience Leading The Way: Peer Support in Mental Health', online: <http://www.together-uk.org/uploads/pdf/SUID/livedexperiencereport.pdf>, accessed 30 June 2011.
- Bataille, G. (1962) *Erotisme: Death and sensuality*. San Francisco, CA: City Lights Books.
- Beresford, P. (2003) 'User involvement in research: Connecting lives, experience and theory', Making Research Count Conference, University of Warwick: <http://www.2warwick.ac.uk/fac/soc/shss/mrc/userinvolvement/beresford/>
- Bertram, G. and Stickley, T. (2005) 'Mental health nurses, promoters of inclusion or perpetrators of exclusion?', *Journal of Psychiatric and Mental Health Nursing*. 12: 387–395.
- Brown, B.J. and Baker, S. (2012) *Responsible citizens: Individuals health and policy under neoliberalism*. London: Anthem Press.
- Cayton, H. (2007) 'Voice piece: Harry Cayton – National Director of Patients and the Public, Department of Health', *Local Involvement Networks (LINKS) Bulletin*. 1: 2.
- Chamberlin, J. (1998a) 'Citizen rights and psychiatric disability', *Psychiatric Rehabilitation Journal*. 21: 405–408.
- Chamberlin, J. (1998b) 'Confessions of a Noncompliant Patient', *Journal of Psychosocial Nursing and Mental Health Services*. 36: 49–52.
- Clarke, J. (2005) 'New Labour's citizens: activated, empowered, responsabilized, abandoned?', *Critical Social Policy*. 25: 447–463.
- Cohen, O. (2005) 'How do we Recover? An Analysis of Psychiatric Survivor Oral Histories', *Journal of Humanistic Psychology*. 45: 333–354.
- Cowden, S and Singh, G. (2007) 'The "User": Friend, foe or fetish? A critical exploration of user involvement in health and social care', *Critical Social Policy*. 27: 5–23.
- Crepaz-Keay, D. (2010) WHO Regional Office for Europe Empowerment in Mental Health – Working together towards Leadership http://www.euro.who.int/__data/assets/pdf_file/0018/124560/E94377.pdf.pdf, accessed 29 April 2012.
- Croft, S. and Beresford, P. (1995) 'Whose empowerment? Equalizing the competing discourses in community care', In Jack, R. ed. *Empowerment in community care*. (pp. 59–76) London: Chapman and Holt.
- Dearden-Phillips, C. and Fountain, R. (2005) 'Real Power? An examination of the involvement of people with learning difficulties in strategic service development in Cambridgeshire', *British Journal of Learning Disabilities*. 33: 200–204.
- Department of Health (1999) *National service framework for mental health*. London: The Stationery Office.

- Department of Health (2000) *The NHS Plan: a plan for investment, a plan for reform*. London: The Stationery Office.
- Emerick, R. E. (1996) 'Mad liberation: The sociology of knowledge and the ultimate civil rights movement', *The Journal of Mind and Behaviour*. 17: 135–160.
- Everett, B. (1994) 'Something is happening: The contemporary consumer and psychiatric survivor movement in historical context', *Journal of Mind and Behaviour*. 15: 55–70.
- Foucault, M. (1971) 'Revolutionary action: "Until now"', *Actuel*. 14: 42–47.
- Foucault, M. (1977) 'Preface to transgression', In *Language, Counter-Memory, Practice, Selected Essays and Interviews by Michel Foucault*. (Ed. Bouchard, D.) Ithaca: Cornell University Press, pp. 29–52.
- Harding, C. M., Brooks, G. W., Ashikaga, T., Strauss, J. S. and Breier, A. (1987) 'The Vermont longitudinal study of persons with severe mental illness, II: Long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia', *American Journal of Psychiatry*. 144: 727–735.
- hooks, b. (1994) *Teaching to transgress: Education as the practice of freedom*. London: Routledge.
- hooks, b. (2003) *Teaching Community. A pedagogy of hope* New York: Routledge.
- Kelly, M. and Gamble, C. (2005) 'Exploring the concept of recovery in schizophrenia', *Journal of Psychiatric and Mental Health Nursing*. 12: 245–251.
- Kumar, S., Guite, H. and Thornicroft, G. (2001) 'Service users' experience of violence within a mental health system: A study using grounded theory approach' *Journal of Mental Health*. 10: 597–611.
- Leiberman, R. P. (2002) 'Future directions for research studies and clinical work on recovery from schizophrenia: questions with some answers', *International Review of Psychiatry*. 14: 337–342.
- Mäkitalo, A. and Säljö, R. (2002) 'Invisible People: Institutional Reasoning and Reflexivity in the Production of Services and "Social Facts" in Public Employment Agencies', *Mind, Culture, and Activity*. 9: 160–178.
- Masterson, S. and Owen, S. (2006) 'Mental health service user's social and individual empowerment: Using theories of power to elucidate far-reaching strategies', *Journal of Mental Health*. 15: 19–34.
- Neuberger, J. and Tallis, R. (1999) 'Do we need a new word for patients?', *British Medical Journal*. 318: 1756–1758
- Ramon, S., Healy, B. and Renouf, N. (2007) 'Recovery from Mental Illness as an Emergent Concept and Practice in Australia and the UK', *International Journal of Social Psychiatry*. 53: 108–122.
- Sayce L. (2000) *From Psychiatric Patient to Citizen: Overcoming Discrimination and Social Exclusion*. London: Macmillan.
- Sumner, C. (1990) *Censure, Politics and Criminal Justice*. Milton Keynes: Open University Press.
- Wilkinson, J. (2001) 'The politics of risk and trust in mental health', *Critical Quarterly*. 46: 82–102.