

## **The rise of the service user: Are some service users more equal than others?**

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Soundings, 40: 18-28, 2008.**

### **Preamble: Our stories**

Our authorship of this article reflects our standpoints as a long term service user with bipolar disorder (SB), her carer (BB) and a social work practitioner turned educator (HG). During the course of SB's struggle with complex and enduring mental health needs, both BB and SB became social scientists who are now working in UK universities. Our experience reflects our engagement with a diverse range of institutions and styles of delivery, including hospital, community and primary care. Most of our experience has been in North Wales, and the events reported in this article reflect the historical progression of services there over the past three decades as a greater emphasis has been placed upon service user involvement and consultation. Our ongoing interest in this topic has led to our discovery of many more accounts from other parts of the UK, so the experiences reported here have a broader resonance with the provision of mental health care elsewhere and aspects of what we witnessed have also emerged from inquiries into a number of high profile tragedies in the sector.

Sally Baker's path through the system from the early 1980s to the present day traces many of the key debates and policy changes in mental health practice and delivery. At the start of her difficulties as a young adult she was referred by her GP to a psychiatrist whose line of questioning was by turns informed by discredited psychodynamic theories and biomedical determinism, and included a request that she submit to an intimate physical examination. Upon leaving the consultation and subsequently expressing her disquiet to her GP she was told 'you're not allowed to complain, he is answerable only to himself'. At that time the critiques of psychiatry by Szasz and Laing were still ringing in our ears, and their exposure of the injustice of psychiatry, with the privilege of its practitioners to define reality and populate their notes with grotesque caricatures of patients' experiences spoke to our frustrations.

### **The moral career of a 'mental patient'**

These impressions of a mental health service which was a law unto itself were reinforced as the 1980s wore on when Sally was admitted to the now defunct North Wales Hospital at Denbigh. Here, many patients were detained involuntarily and where treatment was available it took the form of medication. Despite the variety of presenting problems, this usually took the form of largactil. Curiously, given the alacrity with which the prescription pad was wielded in the case of purported mental illness, the physical care of the patients was limited. It was often not possible for them to obtain treatment for ongoing and disabling medical conditions and professional dental care was unavailable. Once again the power of particular consultant psychiatrists to impose their idiosyncratic notions upon the whole spectrum of care was apparent. One psychiatrist in particular used his practice as a platform to develop an extensive network of private nursing homes, sex therapy facilities and even recruited the more complaisant women patients to serve as his personal housekeepers and childminders. Such was his status in the small community of practitioners in North Wales that no one was able to challenge him. More junior doctors soon moved on to other posts, and nurses were cowed by the sheer minatory power of medicine and doctors' status. In practical terms, patients had little chance of redress if they complained. As a clinical psychologist in the West Country told us in 1986 'patients are mangled if they complain'.

Despite the overwhelming atmosphere of neglect and squalor, some members of staff exhibited considerable kindness and friendship to patients, some of whom were at a very low ebb indeed. Despite their dissatisfaction with the hospital, some expressed their fears of what would happen if the mooted move to community care were implemented as 'there aren't any facilities in the community'. Policymakers and managers, they felt, had underestimated the level of need of some very vulnerable people.

Another of Sally's experiences in the mid 1980s highlighted the piecemeal and sometimes contradictory responses of these kinds of regimes to clients in distress.

On being readmitted to hospital as a result of a suicide attempt, one of the catering staff offered her an extra Eccles cake for supper, one of the nurses cried and three other nurses were verbally abusive. One of the latter physically assaulted her three days later, saying it was tempting to beat her up and that he wished her suicide had succeeded. On making a complaint about him Sally later discovered he had transferred to the secure unit at Park Lane Hospital on Mersyside. Perhaps the kindest interpretation which could be placed upon these events was that staff were unable to cope with their own emotions on seeing patients' problems. Moreover, as far as we could see, there were no mechanisms in the organisation for them to learn appropriate protocols, or to safeguard their own wellbeing, when confronted with clients in distress. Thus, their anger with the patients in their care was allowed to flourish unchecked. As the old adage had it, the staff were as institutionalised as the patients.

### **The 1990s –a decade of reform?**

Despite the apparent solidity of the institutions in which Sally was incarcerated, many of them were not to survive to the turn of the century. The 1980s gave way to the 1990s and with the new decade the impact of deinstitutionalisation became more apparent. Older hospitals shed their beds, the power of doctors was eroded and where it was still available, residential care was undertaken in smaller, more modern units. Scholars of health care reported upon the friction between health practitioners and a new breed of cost conscious, business oriented managers who were increasingly finding footholds in health care organisations. The 1990s also saw a growing trend towards user involvement and empowerment as the new business ethos was accompanied by the rhetoric of a commercial consumer focus.

In 1992, Sally attended the initial meeting for the establishment of a psychiatric patients' council for the North Wales region. A representative from MIND Cymru arrived and told the assembled patients that 'we're not allowed to call ourselves patients anymore, we've got to call ourselves services users'. A number of patients objected to this term but the MIND representative was adamant – she admitted that lots of people don't like being called service users 'but that's what we're called now'. By fiat then the status of patients or clients was changed to that of service users.

This new consumerist spirit might at first have seemed to offer a more client-focused emancipatory approach to people and their problems. This spirit of empowerment seemed to offer a response to the erstwhile critics of psychiatry and a genuine alternative to the coercively applied, one-size-fits-all institutional regimes which had persisted into the 1980s in some regions.

Yet it soon became apparent that there were limits to this empowerment. The concept was used in mental health with little reference to any sociological theories of power. There is much talk of 'empowering' 'service users' in mental health, but as the radical educationalist Paulo Friere noted, the 'empowered' are not the same as the powerful.

The first intimations that all was not as it seemed in the new world of service user empowerment were observed by Sally during a stay at Springfield Hospital in South London in the early 1990s. During her time there Sally attended a ward meeting at this teaching hospital, which prided itself on being at the forefront of the new trend to consult patients, before this was accepted policy. At this meeting virtually every 'service user' on the ward made angry complaints about one very abusive and threatening patient. It was said that she was receiving 'special treatment' because, they claimed, there was a close relationship between her family and the medical staff at the hospital. They felt it was unacceptable that during their time in hospital they should be subject to bullying and intimidation. The ward manager shouted at the newly 'empowered' service users that they were not to comment about this matter and that was that, he wouldn't listen to such complaints. Sally commented that this was a strange sort of democracy and was told that she would not be welcome at any future patients' meetings. Since then, this hospital has been at the centre of a number of scandals and tragedies, involving patients killing staff and members of the public. In 2000 it was accused of 'serious management and systems failures' by an independent inquiry into one such death, chaired by Peter Herbert. The hospital was said to have 'systematically underestimated' the risks posed by patients to themselves and to others. Perhaps, then, the service users had a point.

A further vignette showing the limits on service user empowerment was provided by another of Sally's experiences in North Wales. This brought home to us how service providers are adept at deploying the rhetoric of service user involvement in order to achieve their own objectives, no matter how unpopular these are with the wider service user body. It can be used to legitimate withdrawals of provision, or to reduce standards of service, or to convince regulatory authorities that all is well in troubled services dogged by controversy and complaint. We are aware of instances in different regions of Wales where popular day centres run by the statutory services were closed in the face of local protest. The authorities involved claimed that 'service user consultation' informed the closures. Naturally, the authorities had made decisions about where and where it was not appropriate to involve service users and even appear to have classified them into the kinds of service users whose views can be taken seriously and those whose opinions need not.

In the cases we are aware of, the service user groups were dominated by a small clique of users who appointed a single spokesperson. These spokespeople were not necessarily representative of the views of the wider group. In the case in which we were most closely involved, the spokesperson had a very poor relationship with many of the service users he claimed to represent, and a number of people were frankly suspicious that the hospital authorities were telling him what to do. A meeting was organised with service users and 'management' to 'discuss' whether the day centre should remain open. Sally attended this meeting, which involved the service user representative, as well as a senior nurse and an NHS manager in addition to an audience of service users. 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 the nurse and manager. This angry scene was occasioned by one service user announcing that he had discovered how a consultant in the Trust had been given a 'meritorious award' (presumably a 'merit award' under the performance related pay scheme in operation at the time) for organising the closure of the centre, and demanded to know if this was true. The service user chairman helpfully told the manager that he didn't have to answer that if he didn't want to. The manager declined to answer. The patient then repeated the question directly to the manager. He was told by the senior nurse that all questions had to go through the chair. A

number of those present 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 indeed closed and the manager was reported in the local press as saying that there had been extensive consultation with service users in reaching this decision. The service user representative who chaired this meeting subsequently achieved notoriety at a service user conference by telling the assembled company that 'my job is to do what the NHS wants'.

This kind of experience fed our suspicion that service user involvement was being implemented as a cosmetic solution to the problems of engaging stakeholders in the planning and delivery of services. It is often not facilitated in a way that will yield substantive gains in the quality or acceptability of services and therapeutic interventions, nor in the effective management of risk and the enhancement of client wellbeing. People who are in crisis and who most need to be engaged by services if tragedy is to be averted are often overlooked by such ventures.

The impact on the quality of service of service user involvement and consultation is further illuminated by Hefin Gwilym who worked as a social worker in the field of mental health in North Wales for a period of five years between 1999 and 2004. On the face of it these were heady times for the notion of service user involvement in mental health care. The National Service Framework had just been published by the Department of Health, foregrounding the importance of service user involvement at every level from service design and planning to the provision of individual therapeutic programmes. During Hefin's time as a social worker it was possible to see at first hand both the good and the bad side of service provision for very vulnerable and distressed people. Undoubtedly, there are many people within the service who have a personal commitment to do their best for the people they work with. There appeared to be people working with strong personal integrity, a genuine interest in research and training in their field, and the ability to fully empathise with the people that they were trying to help. However, as a social worker practicing in the field you soon realise where the problem areas are and you try to protect the people you are supporting by avoiding these areas as far as possible, like the 'street level

bureaucrats' famously described by Michael Lipsky. At the outset, it was clear how hard-pressed the staff at the local psychiatric units were with chronic under-staffing and staff turn-over. One quickly realised that the staff are not managing to fulfil all their responsibilities to the patients. It was clear that there was low morale and that staff are not able to cope with the demands of the job. There were signs of patients being ignored and treated discourteously. For example, as a social worker visiting psychiatric units one would often see very needy patients trying to talk with staff at the ward office and being ignored, or having the office door shut in their faces. In one establishment staff used to call the ward office 'the goldfish bowl' because it was an enclosed area with windows looking out on the ward. This created a them-and-us environment which appeared to be humiliating for the patients.

Sometimes as a social worker working in the community one would visit people in difficulty who would specifically ask to be admitted to a mental health facility. It was not uncommon for people who had their first episode of mental illness to make such a request. From the client's point of view, this might make sense, because most people with any other kind of illness would expect to be admitted to hospital. The assumption people made was that the best doctors and the best treatment were to be found in rather than out of hospitals, especially as new patients would have rather high expectations of the benefits of hospital settings. But for Hefin this posed a dilemma, because the accounts from other patients about their bad experiences in psychiatric units suggest that hospital admission might make things worse. These were stories about having personal property stolen, personal privacy violated, boredom and very few opportunities to talk to staff about the personal and emotional problems that they were experiencing. Patients would sit around in smoke-filled rooms watching television or walk aimlessly around the ward. When one visited the wards there was little evidence of meaningful therapeutic engagement going on and instead a sense that staff were doing the bare minimum to manage the environment where sometimes very difficult and violent patients were being accommodated. There was a strong sense that being socialised in this kind of environment for a long period of time would wear down the good intentions of most staff. Despite the policy changes and the service user empowerment which had taken place over the previous decade, the institutional situation continued to desensitise staff to the

complex needs of those who are there in the expectation that they might receive care and treatment.

From experience of working in the community it appeared to Hefin that there was some confusion over how best to deal with the problems presented by mental disorders. Some of this arose from the different professional disciplines that make up a multidisciplinary community mental health team, with disagreements not only between disciplines but also within disciplines. With the decline in medical hegemony a number of fundamental uncertainties were exposed concerning how best to formulate clients' problems. The previously predominant medical view that clients' disorders could be seen in a similar way to other illnesses was explicitly countermanded by other groups espousing behavioural and social models. This was compounded by uncertainty over diagnosis, with the majority of clients receiving more than one over the course of a psychiatric career. One consequence of this confusion was that some people went untreated when they might have benefited from a more carefully targeted psychopharmaceutical intervention. Equally, the services dealt with a large number of people who were heavily medicated but who remained 'revolving-door patients'. Other patients had considerable difficulty in complying with their medication in the community, and others still, who were on high doses of multiple medications, never reached a point where they were able to function adequately and have a decent quality of life. The clashing philosophies often resulted in disadvantage to the clients. In the case of action taken under the Mental Health Act, or medication, it was still the case that professionals 'knew best', yet otherwise a curious laissez-faire permissiveness prevailed, especially where this would save money and effort. In the case of a man unable to cope at home who was living in filth and squalor for example it was said 'we don't want to impose our values on him' as a means of deflecting the suggestion that he should be given assistance.

The voice of the service user was often submerged in this environment of ideological differences and confusion within services. Add to this the conflict between hospital based psychiatric units and the community teams and it is not surprising that any genuine movement from the service users would find real influence difficult to achieve. The best staff members in both the psychiatric units and the community



would seek to involve clients as much as possible in their own care. However, beyond these piecemeal attempts, it is hard to recall any other genuine patient involvement in the mental health system. On the front-line, the realities of life on the ward continued the same and the patients were hardly empowered at all.

Where service user consultation occurs, it often involves users being invited only to give an opinion in certain domains, such as catering issues, or matters of décor. We have not seen them included in decisions on matters of policy or budget, nor drawn into debates such as those regarding the benefits or drawbacks of drug therapies, electroconvulsive therapies, restraint or isolation, or matters arising from the use of the Mental Health Act. The domains of activity that canvass service users' views are peripheral to the major part of management activity and clinical work. The claim that service users are 'involved' and 'consulted' is highly questionable is particularly true when one considers the drafting of the present Mental Health Bill or the recent Government ban on smoking in mental health units, where service users' opinions were clearly absent. The people most likely to be challenged by service users are catering or nursing staff, not medical staff, managers, policy makers or politicians.

### **Professionalising the career service user**

The last decade has seen a burgeoning of 'professional service users', enabling service providers to maintain that services are being developed and delivered with service user consultation. Many of these career service users have become 'consultants'. Some have set up agencies offering 'training' and 'consultancy' to trusts anxious to demonstrate a suitable level of service user involvement. The term 'consultant' is clearly more attractive to many service users and providers than terms like 'activist', 'campaigner' or 'survivor'. This language is drawn from business culture, as demonstrated by other terms used, such as 'representatives', 'committee members', 'chairs' and 'directors' of service user groups.

This is very different from the more radical service user agendas of days gone by. For example, when Judi Chamberlin authored *On our own: patient controlled alternatives to the mental health system*, this not only offered alternatives but

questioned the notion of mental illness, as well as the structure of power relations in society. The radicalism still detectable in organisations such as *Mad Pride*, *Lunatics Liberation Front* or *Mindfreedom* does not follow through into the activities of this new professionalised service user involvement. Indeed, the present day service users' movement is strangely deradicalised and institutionalised. The service user representatives that we came into contact with subscribed to mainstream discourses regarding mental health issues and were unacquainted with dissenting views. They were remarkably unchallenging regarding other present day orthodoxies – we were firmly told that 'mixed sex wards are bad' and that people who have been sexually abused 'feel dirty' as if these were undisputed matters of fact.

This interdependency between service user initiatives and the statutory services extends to purportedly independent advocacy schemes too. The service user group running the patient advocacy service in North Wales produced literature advertising an 'independent advocacy service'. Sally Baker was told by the director of this advocacy service that 'we can't really pursue serious complaints against the mental health services because the Trust and Social Services fund this service'. One advocate resigned from this group when her line manager had told her not to support patients if they were making serious complaints. The human cost of this situation was indicated when the mother of a young man who had died while in the 'care' of this Trust told Sally 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 putative 'independence' of the advocacy service seemed to create expectations which it was unable to fulfil.

There are more sinister aspects to the process of advocacy beyond mere ineffectiveness, which are rarely explored in the literature or by policymakers. A number of clients feared that service user representatives were using their positions to gain confidential sensitive information about other patients which was then passed on through casual gossip. Indeed, a representative himself proudly described to us how he was able to gain confidential information about patients in his role as a patient advocate. Although a number of clients told us that they had formally complained about this man's conduct, no member of the service users' group was

able to effectively challenge him and the group had no procedures for dealing with concerns over members' activities. This man remained a 'director' of the service users' group and an advocate until he died. Service user 'representatives' may gain other service users' confidences, they may have received treatment together in hospital or in contexts such as group therapy. There is a potential for the misuse of sensitive information in such cases, particularly if one person is markedly more vulnerable than another.

### **Looking to the future: Layard and beyond**

The therapeutic state is undergoing a process of expansion. In November 2005 Welfare Minister Margaret Hodge described new proposals to expand the provision of cognitive behavioural therapy to a whole variety of people with physical and mental disabilities with a view to getting them back into the workforce. She maintained that if she encountered such difficulties that she would consult a 'lifecoach', but people 'working on a shopfloor' 'get a sicknote'. The expansion of cognitive behavioural therapies under the Layard proposals suggests that talk therapies will soon be much more widely available and clients will often have little choice but to participate. While these techniques may benefit those with straightforward anxieties or depression, the likely success of the new cohorts of rapidly trained therapists in disentangling complex, enduring multiple problems is more debatable.

As more of us become entangled in the web of mandatory therapeutic intervention, the need for a more independent, radical service user voice is more crucial than ever. This needs to proceed on a number of fronts. It is important to examine policy and explore how government initiatives succeed in marginalising and silencing vulnerable people. It is vital also to critically examine the research base upon which treatments are based and develop awareness of effective alternatives. In addition, and perhaps most importantly of all, it is necessary to revitalise the social networks and informal sources of support in which sufferers are embedded. Even the most intensive therapeutic interventions represent only a small part of the time a person spends struggling with a mental disorder. The vast majority of their time in company with others comprises family contact, friendship and even informal contact with catering and cleaning staff in hospital. As epidemiological surveys regularly report,

mental health difficulties affect the majority of the population, either as sufferers or carers, so the service user movement has a potentially vast constituency. Whilst this includes very vulnerable people, it also encompasses considerable strength and expertise. It is this, rather than the co-opted, denatured, deradicalized service user consultant which offers genuinely emancipatory opportunities for change.