Constructing the Service User

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This paper examines the use of the term service user within current psychiatric discourse. It asks what people understand by the term and challenges some possible preconceptions about people described in this way, some of whom prefer the term survivor.

The first use of the term “tranquillizer” in psychiatry has been attributed to Benjamin Rush in 1811. Co-signatory of the American Declaration of Independence, Rush was conspicuously more interested in the principle of freedom than its practice. His tranquillizer was a strap-laden chair with a restraining helmet and close-stool pan suspended beneath to permit emptying the bowel without changing the restraint posture. It would be interesting to ask in what way the restrained person saw themselves. If described by others as a service user, presumably the service being used was a maximum restraint service. With benefit of hind-sight it is possible to speculate that the person might seem a victim of medicine, the aim being one of survival rather than benefit.

A survey of the use of physical interventions in psychiatry might reveal a similar picture. From morphine, cocaine, bromides and chloral, to anti-depressants and methylphenidate via neuroleptics, lobotomy and electro-convulsive therapy, the discipline has used physical means to achieve frequently institutional or coercive ends. Have the people in this system been using a service? Their role seems different from someone visiting an estate agent, paying a solicitor or actively engaging with similar services.

It might be concluded from this that the term service user is a political as well as linguistic device, serving to distract from the nature of the relationship between recipients of psychiatry and professionals. The current rhetoric around the need to take service user views seriously does indeed lead to more responsive services, albeit at the cost of creating fictional divides between people like them (who use our services) and people like us (who presumably don't). There are many instances where professionals will agree that service user input has been highly influential in, for example, the appointment of particular staff, the nature of local research or the provision of training. In Shropshire people receiving psychological therapy services have also been paid for management consultancy, contributing to appointment panels and research design. The local Trust has just agreed that experience of psychiatric services as a patient will be regarded as a qualification, rather than disqualification, for job applicants: the lunatics might actually be taking over the asylum.

So who is the service user ?

One aspect of working closely with the user and survivor movement has been discovering the huge variety of talents and passions common to people who pass through the psychiatric system. It might be suggested that many of us hold stereotypical images of psychiatric survivors, generally uninspiring ones at that. A seminar with psychiatric nurses some years back asked people what they thought of greater survivor involvement in service planning and advocacy. A repeated comment was that there was no point as psychiatric patients were "just mad". Certainly many were poor, impoverished by a benefits system designed on the professionally determined concept of "need" rather than the recipients' wants. Some behaved oddly, some could not sit still for long due to medication-induced tardive dyskinesia. But mad? Some of the most passionate activists in modern psychiatry are service survivors. Visit the website for the European Network of Users and Survivors of Psychiatry (www.enusp.org) for an example. The webmaster is Peter Lehmann, publisher, writer and survivor. The site includes articles, links, commentaries and information generated by survivors on the various iatrogenic effects of psychiatry. The information appears in over 50 languages. The translations are provided by survivor activists around the world: one of my own contributions appeared in Japanese, Arabic and Finnish within days of it being posted. Many professionally run journals would be expected to take months to respond at all, without the translation. I wonder if people have someone as creative and dynamic as Peter Lehmann in mind when they suggest consulting with a "service user".

Since an accident in late 2003 I have been a recipient of health services. These range from an intensive care unit where I was in no position to exercise my much heralded right of choice to receiving invaluable support from a hearing specialist. Somewhere along the way I was seen several times by a clinical psychologist. Yet, at a meeting planning developments in the local doctoral course there was much discussion about the lack of on-going involvement from service users. Clearly, I didn't count. Someone even said, "You're not exactly typical are you Craig?" The appeal to representativeness has been a factor in discounting the user voice for many years. Even when that user happens to be present.

What happens to people in services?

Wolfensberger talks of the "wounds" of service users. These are multiple and start with some kind of rejection due to a person's perceived differences. Such rejection may, of course, be essential for the person's immediate survival and be accompanied by a sense of acceptance into a safer setting. The outcome of service involvement is thus, an initially benignly intended, exclusion. The person has relationships with valued others (friends, family, neighbours, colleagues) changed or broken up and lost. The person may find themselves isolated from such relationships and congregated with people whose common factor is referred to as a disability or other potentially stigmatizing mark. In the new setting the person tends to be moved about a lot, with little control or autonomy, marked with various labels and experiences a decreasing sense of security. People involved in services, particularly as inpatients, for a relatively short time become materially poorer and their new labels rapidly confuse both themselves and professional staff (the difference between the labels schizotypal, schizoid and schizophrenic is an interesting challenge for professionals and patients alike). The outcome of this process can be a sense of being blamed and a burden to the system.

What might this look like in the real world? In 1987 my partner, Jacqui Leal, was admitted to our then local maternity unit for a caesarean section. I left her in a bed near the door that morning and returned later that day. She had been moved as a nurse had been "concerned about the draught." When I called the following day she had been moved again "so the deaf lady could be closer to the television". On the Thursday she was moved “because pre-operative patients come down this end”. Finally, and with newborn baby in tow, she was moved to a private room “because we thought she would prefer some peace and quiet”. A few days later Jacqui and Harriet left for home. We gave the nurses chocolates and flowers. Jacqui’s only request during her stay, for Earl Grey rather than institutional tea, had been regarded as outrageous.

This example is not untypical of internal moves for huge numbers of NHS patients. Given that the recipient was an extraordinarily gifted woman with a partner working in the service it might have been expected that she had some say in the matter. Of course, a pre-occupation with an imminent operation and the utter strangeness of her surroundings removed much of Jacqui’s power. Recipients of psychiatric and learning disability services are in even more potentially disempowering and disabling circumstances.

Our own local psychiatric hospital is one of only three remaining county asylums. Built in 1843 it lay on the periphery of Shrewsbury until the late 1990s when the town expanded to meet it. It now lies adjacent to a residential area, alongside the local general hospital and across the road from an industrial park. It is less physically isolated though in-patients are still admitted alongside complete strangers and expected to live indefinitely with people whom society finds difficult to cope with. Labelling is pervasive as are the effects of psycho-active medication and the benefits trap. Somewhere less like an asylum would be hard to imagine. In describing in-patients as service users we are constructing an idea of both their status and the possibility that the so-called service is there for their use.

Our hospital is unusually progressive in its approach to service user involvement. In addition to PALS and a long-standing Patients’ Council it has, for example, a full-time service user involvement coordinator. Nonetheless, recent projects (for, example, the medication information project – see www.shropsych.org) have highlighted a lack of sense of consultation or genuine involvement on the part of local service recipients. Indeed, some aspects of disabling environments are more prevalent in the hospital than elsewhere (transport to Shelton remains haphazard, buildings are poorly designed and lifts inadequate and defensive attitudes remain amongst some staff creating a hostile environment, or at least an environment where patients are grateful for good treatment rather than expecting it as a human right).

The ways in which the service user position is essentially one of being one down are not limited to wider systems. Kottler[1], for example, has described in psychotherapy the ways in which a therapist might "pretend to be perfect". These include saying something you don't understand while the client pretends they do, hiding behind a pregnant pause, agreeing to work with someone without previous experience of success with people with similar problems, and many more. Each action socially positions the therapist as expert and places the client in a less expert position; despite rhetoric that the client is the real expert and has "the answers". In my, mostly positive, experience of clinical psychology as a patient I faced being told that some my symptoms were clearly the result of brain injury even though my records had been lost and the psychologist had never seen the relevant brain scan. Shortly after, a scan revealed my brain to be, in the words of the neurologist, "beautiful." In retrospect the clinical psychologist's insistence might be interpreted as a way of saying, "you are the brain-damaged patient here, I am the expert."

In summary, the term service users can be seen as, necessarily, placing people in a one-down position, thus justifying the expert status and salaries of professionals and simultaneously creating an illusion that they have power in the service they are using. System survivors are another thing altogether.

Surviving services

It has been noted that activists tend to term themselves survivors rather than users.[2] Vivien Lindow, amongst others, suggests that survivors of psychiatric services might prefer to set up their own support system.[3] At least two successful crisis houses are staffed entirely by volunteers and system survivors.[4,5,6,7] One of these, the Berlin Runaway House was recently awarded the Ingeborg-Drewitz-Price for its special efforts to save human rights (see www.peter-lehmann.de/laudatio.htm). Similarly the survivor research and advocacy communities are gaining strength. Peter Lehmann is a powerful advocate for a greater survivor voice in the development of psycho-active drugs.[8] There are equally strong voices demanding empowerment; summarized by Rogers and others as greater community activism, heightened self efficacy and more power though knowledge leading to greater optimism and control over the future.[9] As a man constantly drifting between the roles of service user, survivor and health professional, I can but agree.

References

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Dedication

Some years back I followed John Clements as speaker at a Brighton BPS conference. I was, in turn, to be followed by Professor Mary Boyle and it occurred to me that what I had to say would simply disappear into the wealth of surrounding talent. Then John Clements asked a question. He preceded it with some very kind words indeed about my presentation. Better still, we were wearing decidedly similar shirts. Happy days. This one's for John.