

Service users: Individualised involvement or collective action?

Peter Beresford

This is an important time to be taking stock of mental health service user/survivor campaigning and involvement. Big changes are taking place in social care. These will also impact on developments taking place in mental health services, with the plan to trial personal budgets in the National Health Services announced in Lord Darzi's report in July 2008. This article details the past, present and future of the survivor movement from Peter Beresford's personal point of view.

Key words: Survivor movement; Service users; Organisations; User involvement



There is a growing interest in our history as mental health service users/psychiatric system survivors. In July 2008, the Survivors History Group published a valuable new report, *Celebrating Our History: Valuing ourselves*. This reported on a conference, which brought together pioneering survivor activists and interested historians. It is a lively illustrated report which sets down some helpful markers about the timetable, as well as achievements of service user activism. One of the key points it makes is that there are likely to be many histories of survivors, if different experiences and points of view are to be included, and that while it is important to 'get the facts right', each of us may place different interpretations on them.

So I need to make it clear that this is my personal take on the more recent history of survivors, informed by what many other survivors have to say, but personal all the same. I also need to declare my own position. I have been involved in survivor activism for about 20 years. In my experience, such involvement is a bit like a fairground big dipper, quite a lot of hanging around that's the equivalent of queuing for rides, some real excitement and some definite ups and downs! I feel I owe the survivor movement a lot. For me, like a lot of people, it offered the first real



chance to feel that I could be myself, to be among people who would understand me and my experience, with whom I could be honest, who had shared values and goals. A liberating feeling and often the means to a liberating reality. But life is complicated and survivors and our activities are no exception, so it has been a complex journey, which in my view at least, has meant pain as well as gain, creating its own casualties, confusions, false hopes and dawns.

Key current issues

I want to focus particularly on the present and the future, while looking to the past to gain the important insights which history always has to offer us. I also want to highlight what seem to me a series of key points. I believe they offer vital pointers if service users are to be a successful force in shaping the future, both of policy and their lives. The issues that concern me are:

- the location and nature of service user activism
- the role of large traditional mental health organisations
- problems with participation
- divisions developing between service users.

The location and nature of service user activism

This is a point that is strongly made in the survivor history report. The beginnings of survivor activism were based on collective action. Service users came together in their own organisations, like the Mental Patients Union and Survivors Speak Out, with radical agendas addressing the need for broader change to secure the rights and needs of mental health service users. As the report points out, this has changed over the years. Service users have tended instead to operate from organisations and groups connected with the service system, often with a narrower focus on services and the system. Meanwhile, their own organisations have faced major problems securing adequate and secure

funding, and as a result have been vulnerable, often at the mercy of broader funding and other policies. The local survivor groups and organisations that exist are at the heart of the survivor movement, but the repeated message from them is how fragile and under-resourced they are.

The role of large traditional mental health organisations

Over the years, if anything, these organisations have become bigger, with a higher profile and more resources. Most are heavily involved as service providers. I can only think of one that has switched to become a user-controlled organisation, although all to varying degrees have emphasised user involvement and recruited service users to their activities. Each of us will come to our own conclusions about how effective they are and how much they truly speak for service users (certainly they often speak on behalf of them), but perhaps the lack of progress in mental health policy and practice over recent years offers some clues. They continue to gain the lion's share of public funding and ironically it was one of these organisations that secured large scale funding to set up a national service user network, while service users themselves have been starved of the resources to develop their own initiatives.

Problems with participation

Some service user commentators draw a regretful distinction between traditional survivor campaigning and the current emphasis on user involvement. The truth of the matter is that most user involvement, at local and central levels, tends to entail considerable pain, frequently for minimal gain. For service users, the acid test of involvement is what it achieves to improve policy and their lives. So far the results of this strategy are not encouraging, particularly where there are not strong service user-controlled organisations to hold services to account.



Divisions developing between service users

There has been growing recognition over the years of the need for survivor collective action to take full account of issues of difference and to be fully inclusive. In a policy field where institutional racism and discrimination on grounds of gender, sexuality, age and impairment are commonplace, this is crucial and the message has been getting through. But it is another less often discussed cause of division that concerns me here. This is the development of what some have called 'super users'; that is to say people as service users who are felt because of their contacts, networks and experience, to have unfair access to what (limited) opportunities, funds, consultancies and positions are available to service users in the mental health system. Such a perception is damaging and divisive and in my view relates to the fact that many people operate as individuals rather than from service users' democratically accountable organisations. There is, therefore, a potential problem of accountability, related to a democratic deficit.

In my view these issues taken together represent a formidable set of barriers in the way of the success for a survivor movement that has been denied adequate funding, legitimacy or credibility. We should not underestimate the achievements of the survivor movement. They are considerable both in changing service users' own perceptions of themselves and in bringing about some significant change in the wider policy world. But I would also argue for some shifts in strategy and ways of working for the future if survivors are to increase and maximise their impact and resources.

Ways ahead for the future

Here finally are some suggestions about how we might take things forward for the future. I am suggesting some shifts in emphasis. I am also keen that we build on the lessons from survivors' histories.

Disability rights, not psychiatric needs

The psychiatric system shows an amazing capacity to resist reform. Many service users' needs are more likely to be met outside it, especially with new more flexible policies like personalisation and individual budgets. We should shift our emphasis from struggling with the system to meet our 'psychiatric needs', to working with broader disability policy and services to secure our disability rights and entitlements.

Building alliances with other groups

Together we are stronger. As mental health service users/survivors people are likely to benefit from developing stronger links and alliances with other groups of service users, particularly groups that like survivors.

Independent living, not recovery

The government has now signed up to a strategy committed to independent living. This means that ensuring that people have the support and access to mainstream policy and services they need to live their lives to the full. It is a non-medicalised philosophy that is the opposite of 'standing on your own two feet' or accepting you are 'defective'. This is an idea much more in keeping with our rights and needs than 'recovery'. While some survivors value the potential of 'recovery', its dominant definition in policy mainly seems to be about stopping needing support and getting back into employment – hardly a liberatory model.

Rebuilding our own organisations

Building on the policy opportunities that now exist through the government's 2008 Independent Living Strategy, now is the time to refocus on working through survivors' own organisations, rather than being dependent on those controlled by others. A key lesson of successful campaigning is that empowerment and effective involvement are most likely to be achieved through 'self-organisation'. The big charities have a role to play in supporting this development, rather than replacing it. This strategy connects with government policy, which is now framed in terms of supporting the development of a national network of local user-controlled organisations. We must use this rhetoric as a lever for real change and empowerment.

Working inclusively

Finally and perhaps most important is the need for service users to develop their skills and commitment to work in truly inclusive and equal opportunity based ways. Mental health service users are one of the most excluded and devalued groups in society. There's a very big problem if all service users don't have an equal chance to get involved and contribute their ideas, experience and insights. This means developing and operating effective access policies plus challenging traditional formal and informal barriers and exclusions. Many people with other impairments are also mental health service users.

Service users must truly all work together. Doing this through their own organisations offers the best prospects both for personal empowerment and broader societal change – the inspiring aims of the emerging survivor movement a generation ago.

References

Survivors History Group (2008) *Celebrating Our History: Valuing ourselves*. Available from: <http://studymore.org.uk/m080529.pdf> (accessed September 2008).



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