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SPEAKING FOR OURSELVES
An early UK survivor activist’s account

Peter Campbell

Peter has been described as a survivor who has “devoted his life and incredible talents to the pursuit of survivors’ rights and justice”. He is one of the pioneers of the UK survivor movement. In an email interview with Peter Beresford for this book, this is what he had to say.

I first became involved in action by mental health system users/survivors in the UK in the mid-1980s. At that time the range of activity was extending considerably and would be actively involved until at least the end of the century. The three groups I was most involved in were Survivors Speak Out, founded in 1986; Survivors Poetry founded in 1991 and Survivors History Group founded in 2005.

Survivors Speak Out was my prime focus from 1986 to 1996, so much so that I limited my activity in Survivors Poetry within 18 months of being a founder member. There was not enough time for me to devote to the two groups and I felt Survivors Speak Out had my first loyalty. After 1996 I was not involved in a group but spent my energies as a freelance trainer of mental health workers. Then, in 2005, I became a founder member of Survivors History Group, a gathering of mental health system survivors interested in ensuring they should write and research their own histories. This is the only group I am still involved in.

Any discussion of what we call ourselves must start and end in the principle of self-definition. People must always be able to choose how they describe themselves and have that respected. This is important whether they want to call themselves consumers, service users, survivors, schizophrenics, anorexics or the mentally ill. We have been burdened for too long with alien names. We must not alienate others by calling them names they do not own. Having said that, I do have a clear preference of term – mental health system survivor. First of all, I feel that survivor (I am surviving not I have survived) is a positive term and points rightly to the obstacle course of the mental health system that I am endeavouring to survive. But equally important it is not a question of mental health services or psychiatry alone. These are important and can be oppressive but they are part of a wider system, a socio-political system that is founded on prejudices and misunderstandings of people diagnosed with so-called mental disorders. I feel most comfortable thinking of my life in relation to a mental health system. It points to the true nature of my dilemma in a way “psychiatric” survivor or mental health service survivor does not.

The main nature of my action has been in three areas. These have been, first the organisation and activities of the UK networking group Survivors Speak Out (1986 to 1996). Second,
freelance training with mental health workers – especially clinical psychologists, social workers and mental health nurses, with a particular focus on the lived experience of mental health system survivors; the reform of the 1983 Mental Health Act and work on the role and function of mental health nurses. Third and finally, the writing of numerous chapters, usually on the ‘service user/survivor movement’ and allied topics, in various mental health textbooks and including regular articles and book reviews in OpenMind, the bi-monthly and now much-missed magazine of MIND (formerly the National Association of Mental Health) which gave mental health system survivor activists an unparalleled voice for many years.

Much of this work was time consuming. Most of it was poorly paid if paid at all. I believe my last three years work at Survivors Speak Out led me to “burn out”. Instead of planning new campaigns or publications like the very successful “Self Harm – From Personal Perspectives”, I was addressing envelopes, dealing with membership fees, answering personal correspondence and other administrative tasks. The eventual arrival of paid workers brought many managerial challenges. Maintaining the infrastructure of action groups was often less enjoyable than action itself. A fact which may help explain why some groups found it hard to continue long term.

My areas of action included working with mental health system survivors and working with mental health workers. With both groups I emphasised the importance of self-advocacy – individuals and groups speaking and acting for change on their own terms. This made clear at the outset the possibilities of action, of people being the masters of their own destiny. It also encouraged diversity rather than agreed agendas and platforms. The aim was not to replace one dominant force (psychiatry) with another – a monocultural survivor movement.

Alongside self-advocacy speaking and acting for yourself – with particular relevance to services, was advocacy – an innovation of the 1980s. The survivor movement championed the right of service users to have another person support them in voicing their wants and needs or to speak up on their behalf completely. As a freelance trainer I promoted the understanding and practical application of both these concepts. Unfortunately, the very real gain in life choices that resulted, was mystified by the false rhetoric of “user empowerment” which suggested much more was going on than actually was. It is true that service users had more control over their lives, within and outside the system, but they certainly were not equal. People with a diagnosis of a so-called “mental disorder” remain, as ever, a disempowered rather than an empowered group.

The United Nations Convention for the Rights of People with Disabilities (UN CRPD) has not really played a part or been relevant to me and my work. I will be very surprised if the compulsion-free care and treatment the UN CRPD appears to envisage will be introduced in the UK in the foreseeable future. Developments seem to be going in the opposite direction with more, not less, compulsory detention and treatment. It has taken 37 years to outlaw the use of police station cells as places of safety under Section 136 of the 1983 Mental Health Act. If a minor but vital change of this kind is so long in coming, the sweeping changes the UN CPRD encourages seem unlikely to arrive any time soon.

In my view there are three main aspects of our first-hand knowledge. First, knowledge of living in, and receiving, mental health services. Secondly, living with mental distress in society. Finally, first-hand knowledge of the interior experience of distress (the “madness” experience). These are of varying interest to service providers. They are enthusiastic about service users as consumers, not particularly interested in the experience of living in society with mental distress and often uninterested or hostile to first-hand accounts and alternative accounts of distress.

The 1990s were the era of “user involvement” when activists were first invited to contribute their knowledge to community care plans. At the same time they told their life stories in training mental health workers.
By the end of the decade, the service user as conveyor of “consumer expertise” was widely accepted. At the same time another rather different development had been taking place. A number of groups emerged using their first-hand understandings of mental distress to put forward alternatives. The Hearing Voices Network (HVN) and the National Self Harm Network (NSHN) are good examples of these. These groups were radical and their challenge to psychiatric orthodoxy was rooted in first-hand knowledge. Their work helped first hand understanding to gain a new value.

First-hand knowledge does now have a new respectability. But it is not entirely a rosy picture. Professionally derived knowledge is still regularly given a higher value than our first-hand knowledge. Survivor-led research is not respected in the way other research is. It would be good to see our knowledge existing on a level playing field with professional knowledge. It would also be good to see more emphasis on our first-hand knowledge of living with distress in society and see our experience being considered alongside that of other disabled people. Above all else, our first-hand knowledge of the interior experience of mental distress/madness deserves to hold a central place whenever psychiatry is taught.

I see psychiatry in the United Kingdom as a mechanism of social control. Individuals are controlled by being compulsorily detained and “treated” often for considerable periods. Psychiatry is at the heart of a system that creates a second class of citizens; people who can be treated differently even if they have retained the capacity to make decisions. It concentrates on the individual pathology of these people, suggesting that they are incompetent and “do not know what is in their best interests”. Psychiatry acts conservatively, reinforcing social prejudice and fitting its recipients into the status quo, rather than trying to change their social environment. While ostensibly looking only to help the distressed, psychiatry is in fact moulding them for roles as the disempowered.

The big question for the survivor movement is whether to try to improve psychiatry or to build alternatives to it. In the UK, the movement has by and large sought to improve psychiatry, while leaving the deeper problem virtually untouched. In this way they have achieved some important positive change without fundamentally challenging psychiatry as a potentially oppressive practice. In the 1980s there was a constant challenge to psychiatry as a form of social control, but that seems to have receded now. It could be claimed that the survivor movement has been co-opted into the mental health system and its challenge fundamentally blunted. The more radical demands of activists have been almost completely resisted. Whatever its history, by and large the survivor movement has become a reformist enterprise.

Unfortunately, the emergence of Mad Studies coincided with my stepping back from involvement in the survivor movement. In short, I know too little of Mad Studies to make meaningful comments. Having said that, any survivor-controlled initiative that provides a radical critique of psychiatry and seeks to build alternatives to it would have my support. Whether Mad Studies does those things will have to be for others to judge.

Note

1 This was said of Peter Campbell when he was awarded the title of Honorary Doctor of Education in 2010 by Anglia Ruskin University, see https://aru.ac.uk/graduation-and-alumni/honorary-award-holders2/peter-campbell