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From Little Acorns

– The mental health service user movement

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Introduction

In the summer of 1985, service user activists from the United Kingdom met activists from other countries at the Mind/World Federation of Mental Health Congress in Brighton, a coming together that underlined the potential for collective campaigning in this country. That autumn's Annual Mind Conference in Kensington Town Hall was the first national mental health event at which service users made a significant contribution to the programme.

The following year, in January 1986, Survivors Speak Out, the first national network for service users involved in action, was established. At this time, Nottingham Patients' Council Support Group was beginning its work, pioneering collective and individual advocacy. By the end of 1987, National Voices, a service user network within the National Schizophrenia Fellowship (now Rethink) and Mindlink, a similar network within Mind, were up and running and Survivors Speak Out had organised the first national conference of service user activists over a weekend at Edale Youth Hostel. It could well be said that something exciting was beginning to get underway (Wallcraft *et al.*, 2003).

It is tempting to identify the mid-1980s as the time when service user action really started. While there is a great deal of truth in such a view, it does not do justice to action that had taken place before this point. Protest against the mental health system – and protest has usually been a powerful force behind service user action – has occurred ever since the creation of the asylums nearly two hundred years ago. But for a long time protest was, more often than not, emerging from individuals rather than organised groups.

In the 1970s an important group did form. The Mental Patients Union, with branches in various parts of the country, can justifiably be called the originator of organised service user action (Crossley, 1999). When it broke up it was succeeded by a number of smaller groups: Community Organisation for Psychiatric Emergencies (COPE), Protection of the Rights of Mental Patients in Therapy (PROMPT) and Campaign Against Psychiatric Oppression (CAPO). These groups provided a link between action in the 1970s and developments in the 1980s. CAPO, for example, although quite a small group, was influential

in the early 1980s and continued its work into the 1990s. A number of activists who pioneered new groups in the mid-1980s were introduced to action by the above groups and by the British Network for Alternatives to Psychiatry (BNAP), an organisation of mental health professionals and service users that had links with the ‘anti-psychiatry’ movement. If the real flowering of service user action took place in the late 1980s and 1990s, it was through the work of these often-neglected groups that the first seeds were sown.

Nevertheless, it is quite clear that there have been huge changes in the role of people with a mental illness diagnosis over the last 20 years – at least as far as mental health services are concerned. Speaking in broad terms, in 1985 service users were nowhere; in 2005 they are everywhere. Whereas service users were hardly involved directly in the development of the 1983 Mental Health Act, they have played an important role in debates around the current Mental Health Bill. It is unlikely, but not impossible, that any major development in the mental health field would now be undertaken without formal attempts to consult with people with direct experience.

The situation was very different in 1985. Mind and other voluntary organisations were ‘the voice of the mentally-ill’, speaking on their behalf without any coherent means of being sensitive to their true wishes. The few independent service user action groups that existed were unfunded, unappreciated and on the margins. When they did capture an audience they were accused of being extremists with nothing positive to offer.

Such sentiments would not be expressed today, at least not openly, and it is true to say that service users have now been recognised as rightful and valuable stakeholders in the process of developing better services. Service user activists have penetrated areas of the mental health system where their presence, let alone their positive contribution, would have been inconceivable 20 years ago. The fact that service users now run their own services, educate most groups of mental health workers, even provide a research team at the Institute of Psychiatry, the Service User Research Enterprise (SURE), is an indication of the different type of landscape we are now inhabiting. In short, people with a mental illness diagnosis have gone from being an absence to a presence in the mental health arena. Use of the descriptive term ‘experts by experience’ in recent years illustrates the distance that has already been travelled and hints at the potential that has still to be realised.

Drivers for change

It is an open question how much of this transformation can be attributed to service user action alone. There has been a steady demand for ‘user involvement’ from government and service providers and this has been vitally important both in stimulating the steady

growth of action groups and shaping the types of activities they undertake. Frequently the necessity of finding service users to feed the system's need for consultation has been close to overwhelming. Service user groups have sometimes been created solely to meet this demand and it is not fanciful to suggest that if independent action groups did not exist, government would have to create something similar to replace them. So the demand for involvement has a life of its own and creates agendas over which service users may have limited control and which may not always serve their true interests. Having said that, there is no doubt that service user activists have profoundly influenced the way in which people with a mental illness diagnosis have begun to emerge from the shadows and be recognised as an important creative force in their own right.

Part of the success of service user action has been connected with the growing number of people willing to 'come out' and speak openly about living with mental distress. Challenging the secrecy surrounding this subject is essential to meaningful social inclusion and it is possible that such openness will eventually have widespread impact. At present, it is more likely that people will reveal their histories in and around mental health services and be less happy to speak out in other settings. There is even anecdotal evidence that some activists have become more cautious than they were in the latter respect as a result of persistent negative attitudes among the public. Despite the greater presence of people with direct experience in the media, stereotypes of dangerousness and 'alienness' are still prevalent and it is clear that progress remains frustratingly slow. Even so, the importance of mental health workers and service users 'coming out' should not be underestimated. Recent revelations by senior officers of the Royal College of Psychiatrists about their experience of mental distress would have been highly unlikely 20 years ago and illustrate the changes that are beginning to take place (Friedli, 2004a).

An important aspect of the development of action has been the growth of independent service user groups. These have formed the bedrock for activity, although it is important to recognise that work by activists on their own or within voluntary organisations for people with mental distress has also made a significant contribution. It was by no means inevitable that action would be focused around independent service user-led or service user only groups. In this respect, the fact that Survivors Speak Out, an organisation dedicated to support the formation of independent groups, was the first national network to be established was probably significant. Its existence helped ensure that new action did not become entirely directed through large voluntary organisations like Mind or the National Schizophrenia Fellowship (now Rethink).

The extent of the service user movement

It is difficult to be certain about the current number or character of service user action groups. The *On Our Own Terms* research report, (Wallcraft *et al.*, 2003) which covered England, developed a cleaned database of 896 groups. A recent article (Friedli, 2004b) suggests that there are 700 across the United Kingdom. There are problems in obtaining an accurate picture, partly as a result of the creation and disappearance of local groups, partly because it is not always easy to discover whether groups are service user-led, service user only or attached to voluntary groups. It is also true that people do not always use the same definitions to categorise them. These are interesting questions and important in any attempt to define a detailed description of what is going on. But in terms of providing a general picture of developments in the last 20 years, it is sufficient to say that there are now substantially more than 500 groups whereas in 1985 there were around a dozen.

From a base of about 50 groups at the end of the 1980s, growth in numbers accelerated through the 1990s. There can be little doubt that the NHS and Community Care Act 1990 (House of Commons, 1990) stimulated the formation of groups by requiring services to consult with their users. Statutory and voluntary organisations became more active in supporting service user action. User development workers began to be employed. Part of their brief was usually to establish forums through which the service user voice could be better heard. Funding, although not generous, was more available than in the previous decade. At the same time, service providers' requests for consultation had an effect on the character of action groups. Few felt strong enough to resist these requests even if they wanted to. The experience of being ignored or on the margins meant that involvement, on whatever terms, seemed too important to turn down. As a result, groups became more closely tied to the service system than groups in the 1980s that were more able to retain a separate position, offering criticisms and proposals from outside services.

The late 1980s and early 1990s also saw the establishment of a number of networking groups. These included the United Kingdom Advocacy Network (UKAN), the Scottish Users Network and the US-Network, covering Wales. Networks dealing with particular aspects of the service user experience became active, including the Hearing Voices Network and the National Self-Harm Network. The Manic Depression Fellowship became a service user-led organisation. During the 1990s, local groups set up by people from Black and ethnic minority communities also began to develop. On an international level, service users from the United Kingdom were involved in the creation of the European Network for Users and Survivors of Psychiatry. This level of activity was something different from what had gone before, albeit that some activists complained that action had lost its radical edge. Even so, the work in England of the Mental Health Task Force User Group (1992-1994) which collaborated with the Department of Health Mental Health Task Force to produce a number of important publications was seen as a significant success. The possibility of influencing policy at a national level, an opportunity that has not yet been properly realised, seemed quite realistic at that time.

The achievements of the movement

Before considering the types of action in which groups have become involved, and their successes and failures, it is worth noting the organisational achievements of the last 20 years of action. The successful existence of so many groups is witness to the way in which the activists' belief in the principles of self-organisation and self-help has been put into practical effect. Although some groups have been short-lived, many have been operating for ten years or more. The skills and long-term commitment required have been considerable and these are among the qualities which people with a mental illness diagnosis are popularly supposed to lack and be unable to acquire. Nevertheless, large numbers of activists, who at the time of their first involvement did not have organisational experience or expertise in collective working, have successfully acquired these skills. The fact that they have very often been working in small, under-funded organisations may actually make their achievement more remarkable. It is certainly not the case that keeping action groups up and running is an easy task and groups have had to come to terms with the ongoing mental distress of their members. Burn-out has been a feature. But these problems are not exclusive to service users. The creation and maintenance of action groups clearly demonstrates that the capacities of people with a mental illness diagnosis have been routinely underestimated. Sooner or later this revelation must penetrate mental health services and beyond.

Action has become very diverse and, as has already been suggested, service users have influenced most aspects of mental health services. These include: consultation and monitoring in connection with existing services and input into the development of new services; provision of training and education to all groups of mental health workers and involvement in selection of employees; undertaking service user-led research; creating and running service user-controlled services; and promoting new understandings of mental distress. Although local groups are unlikely to be involved in all these areas, most will be active in more than one. While action has always been largely concerned with mental health services, groups have also undertaken artistic activities and provided mental health awareness education to the general public. Work with the media has been an increasing concern.

Much of the contribution of service user activists has been made at a local level and there has been a limited amount of research detailing the impact of local action across the country. It seems likely that important but small-scale changes in the nature of services have been achieved rather than dramatic 'bricks and mortar' transformation. Attitude change and greater sensitivity and flexibility in the day-to-day running of local services have certainly begun to occur. Long-standing grassroots demands for independent advocacy and patients councils have also given service users more influence over their care and treatment and the environments in which they take place.

Obstacles to be overcome

It may be a cliché to suggest that while much progress has been made much more remains to be done, but there is a good deal of truth in such a generalisation. At this stage in the development of service user action there is a danger in being over-impressed, because of the low base from which action began. A number of obstacles continue to limit the service user contribution. These need to be acknowledged and overcome in the immediate future.

Credibility remains a crucial issue. In an evidence-based culture, evidence from service users frequently fails to measure up to ‘scientific’ standards.

The issue of representativeness has been a bugbear for action groups throughout the last 20 years and has never been tackled in an open way, allowing service providers to control when contributions from service users are taken seriously or not. The basis for such choices has usually not been made clear. Mental health professionals have regularly warned of the ‘professional user’, a slur which suggests that activists are not real service users and are not in contact with their constituency. It also betrays an anxiety and hostility around the fact that people with a mental illness diagnosis began to self-organise in a way professional groups have been doing for many years. By questioning the legitimacy of action in these ways, the establishment ensures that it remains in control.

As involvement has moved on from consultative work to other areas, concerns about credibility have continued. Service user-led monitoring and research (Rose, 2001; Mental Health Foundation, 2000) has often been undermined as not being ‘real’ research and lacking in scientific objectivity. The development of new understandings of aspects of mental distress like self-harm or hearing voices (Pembroke, 1994; Romme & Escher, 1993) has met with official scepticism for similar reasons. While consultation is a more acceptable, but still subtly controlled, activity, work in the above areas provides a far greater threat to the power base of the mental health establishment and so must be kept at arm’s length. Despite the progress of the last 20 years, it is quite clear who is pulling the strings when it comes to the control of knowledge and understanding.

In view of this, it is not surprising that messages from people with direct experience take so long to have an impact. Mental health services grind extremely slowly. We are now in the midst of an epidemic of concern about acute care that has been intensifying since the late 1990s. Service user activists have been complaining about conditions on acute wards since the late 1980s (Good Practices in Mental Health/Camden Consortium, 1988). Suggestions about improvements and alternatives have been forthcoming over a similar period but have only latterly led to concrete results, for example ward round codes and crisis houses (*Openmind*, 2004; Mental Health Foundation/SCMH, 2002). Advance directives, now widely canvassed by professional and voluntary organisations in relation to a new Mental Health Act, were first taken seriously by service user action groups. In the

mid-1990s, Survivors Speak Out was the first organisation to produce guidance for service users on writing their own advance directive. Without betraying too much bias, service users can claim to be providing many of the good new ideas in the above and other areas. Service providers' responses would benefit from some acceleration.

Resources are a major factor limiting the effectiveness of service user action. A great deal has been achieved on very little. While government and service providers' expectations and demands for input have steadily increased over the years, resources have usually not grown to match them. Although service user action groups are no different from other voluntary organisations in their dependence on unpaid work, there is a limit to the extent and quality of involvement that can be sustained without a greater commitment of resources. It is hard for activists not to detect the controlling arm of the establishment when it comes down to giving and denying money. Action has moved on in many ways and there are a much greater number of service users employed in the 'service user involvement industry' than there were in the 1980s and early 1990s (Snow, 2002). Nevertheless, there is a great imbalance between rhetoric and practice when it comes to funding. The service user contribution cannot be maintained, let alone developed, until this issue is successfully addressed.

The balance of power

Empowerment has become an important concept in recent years, particularly in regard to the lives of people who are long-term users of welfare state services. Apparently, mental health service users are becoming empowered. Like other fashionable concepts, partnership for example, empowerment can be used to soften or obscure realities as well as reveal them. Nevertheless, it is now so ubiquitous that it may be useful to look at the experience of people with a mental illness diagnosis in terms of their ability to control significant aspects of their lives.

Baldly stated, people with a mental illness diagnosis remain what they have always been: a fundamentally powerless group. While acknowledging that there have been recent improvements in their status, it is still clear that both in relation to mental health services and their position in society they reside somewhere near the bottom of the pile. The Disability Discrimination Act (1995), the Human Rights Act (1998) and the *National Service Framework for Mental Health* (DH, 1999) can with justification be called steps in a better direction. But they do not alter the basic reality. In 2005, people with a mental illness diagnosis are on the lowest rungs of the hierarchy of power. There are a number of factors that help ensure they will stay there for the foreseeable future.

Perhaps the most important of these is poverty, an issue that service user action groups could have done more to highlight in recent years. Poverty is a dominating feature in the lives of service users, robbing them of effective control of their destinies and diminishing

the quality of day-to-day existence. Most of the experiences that cause mental distress are directly linked to a lack of money: poor housing, poor nutrition, lack of leisure opportunities, boredom, isolation and hopelessness. Many service users are unable to get out of the house and travel about locally unless they are lucky enough to have a free travel pass. A social existence of this nature cannot by the remotest stretch of the imagination be called empowering, no matter how much more involved service users are in their care and treatment. Looking back over the last 20 years and the increasing inequalities in British society, it is hard to feel optimistic that substantial changes are likely in this crucial area in the near future. Powerlessness linked to poverty is likely to remain a fundamental stumbling block.

Discrimination is another major obstacle to empowerment. While it is possible to argue that there is now more social awareness about 'mental health problems', public attitudes have not changed substantially. People may feel freer to talk, write or broadcast about a range of psychological problems. But psychosis is pretty much off limits and schizophrenia still fundamentally unspeakable. Since the public woke up to the reality that 'the mentally ill' were no longer being taken care of in the remote (in all senses) asylums, there is evidence that attitude change has been as much negative as positive. Certainly fear and preoccupation with perceived violence has increased. It is not clear that greater presence in the community has enabled people with a mental illness diagnosis to appear any less alien to the majority.

In some respects, everyone involved in the mental health field, service user activists included, may have been naive in hoping that somehow the best way of developing community care was to slip it in and hope that the community would not really notice. Perhaps the fact that the experts did not then know, and to an extent still do not know, how to effectively change public attitudes and behaviour had something to do with it. Whatever the reasons, people with a mental illness are still reduced to powerlessness through discrimination and denied any real equality of status. It invades every aspect of their lives. A survey of 778 service users (Read & Baker, 1996), which found that 47% had been abused and harassed in public and 26% had been forced to move home as a result of harassment, made the oppressive and tangible nature of discrimination very clear.

Mental health services have become more empowering. The opportunities for service users to influence their own care and treatment are greater now than 20 years ago. In this respect, the growth of independent advocacy, a steady development that owes much to the commitment of service user activists, has had a positive impact. Even so, there are still very basic shortcomings. Complaints about the amount and quality of talking and listening have not diminished. Service users still often feel they are not taken seriously or given sufficient information, particularly around medication. Respect and dignity are regularly demanded.

While the Department of Health claims that there is widespread satisfaction with services overall, numerous small scale surveys have revealed major disquiet among service users at aspects of the system. It does not seem impossible that satisfaction is linked to some

extent to low expectations. At the same time, opportunities for individuals to become more involved are not always realised. Even after nearly 15 years, the Care Programme Approach, a significant step in putting service users at the centre of their care, does not seem to be operating effectively in parts of the country. Research evidence suggests that involvement in CPA, indeed even awareness of it, can be limited (Rose, 2001).

Any assessment of empowerment within services must take account of the Mental Health Act. On the face of it there are contradictions within a service that seeks to give its users more control over their lives and yet is prepared to exercise, increasingly, powers to detain and compulsorily treat them. The fact that this can happen legally, even when the individual retains the capacity to make treatment decisions, must be seen as an extreme form of personal disempowerment. Nor should its disempowering effects on people who are not detained under the Act but are potential detainees be underestimated. It is possible to see the Mental Health Act as a significant factor in the diminished status of people with a mental illness diagnosis.

Most service user activists have campaigned against any extension of compulsory powers. They have fought this issue consistently since the first proposals for Community Treatment Orders in the mid-1980s. Although they can claim some success in helping delay developments, it now seems almost certain that they will have to admit defeat and watch as the government increases its power to intervene in their lives and extend compulsory treatment powers into the community.

This is a significant rebuff to the beliefs underpinning the service user contribution in recent years, and in the eyes of many activists calls into question the sincerity of the current Government's commitment to empowerment and partnership. Moreover, it seems to confirm increasing suspicion that when it comes to the crunch, government will always respond more enthusiastically to the demand to control people with a mental illness diagnosis than to empower them. It is scant consolation that so many voluntary and professional organisations are now throwing in their lot with service user activists over the issue of compulsion.

Conclusion

From an activist's point of view the current period is a time of uncertainty – uncertainty about the future for service user action and about the future for people with a mental illness diagnosis as a whole. While life is more likely to be lived in the community rather than institutions, it is still far from clear on what terms that life will be lived or what its quality will be. On the one hand, the Government has recognised social exclusion as an issue and produced a useful report setting out ways of challenging it (SEU, 2004). On the other it seems content to go along with exaggerated fears of risk and dangerousness and tip mental health services further towards social control.

Even the recent growth of interest in creating employment opportunities has a darker side relating to the Government's desire to reduce the numbers of people with mental health problems on Incapacity Benefit. Already fears are growing that there will be greater commitment to decreasing overall benefit payments than to ensuring people are not shunted off into insecure and low-paid employment. At the same time, there is a continuing refusal to reward the contribution of service users on benefit towards the development of mental health services. In many respects, convincing signs that society is really interested in bringing any group of disabled people in from the margins are hard to find. The struggle for equal citizenship has a long way to go and it is not clear how well-equipped people with a mental illness diagnosis are to influence the outcome.

But, despite this, it is certain that service user action is not going to go away. A degree of permanence has been achieved and there are a number of challenges for the immediate future. One of the most important is to extend the involvement of minority groups in action. This is particularly relevant to Black and minority ethnic service users. Although there is a danger of underestimating their contribution in recent years, they have been under-represented in action and as a result their issues have not gained the priority they deserve.

Consideration also needs to be given to the type of alliances action groups establish. Much of the last 20 years has been devoted to work in collaboration with mental health professionals rather than other groups with similar experiences to service users. As issues to do with social inclusion and discrimination become more important there is an argument for developing alliances with other people with disabilities and other groups of welfare state users.

The demand for action is likely to continue because service providers will go on requiring 'user involvement' and because activists will want to open up other areas. Better organisation and co-ordination between groups will become more essential. There is an argument that a clearer ideology has become necessary to challenge biomedical orthodoxies that will always disempower. Certainly, it would be helpful if there was a clearer statement of shared beliefs and objectives. In the past many service user activists have been reluctant to create an overarching organisation that might claim to promote 'the service user voice' at a national level. This is beginning to change and a number of activists have been coming together to discuss setting up a broad forum that might increase the impact of action and develop a greater national presence. After 20 years, the issue of effectiveness has become particularly important.

Energy has never been a problem. Activists have been notably pragmatic up to now. Within mental health services there are a significant number of people, across all professional groups, who are willing to continue learning from the direct experience of people with a mental illness diagnosis. Services are more responsive. New understandings are being explored. Practice is starting to alter. In the next few years it will be interesting to see if activists can change services more radically while at the same time turning attention to a society largely untouched by service user action.

From Little Acorns – The mental health service user movement is a sample chapter from Beyond the Water Towers

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