CHAPTER 13

Madness, Distress, Research and a Social Model

Peter Beresford

Introduction

The focus of this chapter is on research and a social model approach from the perspectives of mental health service users/survivors. Three major points need to be made by way of introduction to this discussion.

First, it is important to remember that the initial attempt made by people, as subjects of and categorised by social policy, to develop a social approach to and understanding of their situation and identity, from their own perspectives, came from disabled people and the disabled people's movement. It is also important to be aware that while this is a relatively recent development, emerging in the 1970s, in another sense it is now well established. It is thus a development that already has its own history, body of written and recorded knowledge and wider legacy in the consciousness of disabled people. This means that a social model approach is particularly associated with disability and disabled people and tends

to be understood primarily from these perspectives.

Second, it needs to be said that mental health service users/survivors have never been central to the social model of disability. The corollary of this has been that for a long time, the social model of disability has not had any particular significance for most mental health service users/survivors. The social model of disability grew from and has primarily been concerned with the experience of people with physical and sensory impairments. Over time, awareness of it has grown among other groups of people subject to or eligible for health and social care policies and services, including older people, people with learning difficulties, Deaf people, black people and members of minority ethnic groups and mental health service users. There has been some critical debate from these different groupings about both the degree to which the social model of disability has taken account of their situations and perspectives and how applicable it might be to them (Morris 1996; Corker 1998; Docherty et al. 2003). It cannot really be said that there has been a strong sense of shared ownership of the social model or that it originated with the concerns of mental health service users/survivors specifically in mind.

Third, it is necessary to make clear the dynamic state of discussion about the social model of disability. From the time since Liz Crow first wrote critically about the social model as a disabled woman, it has been subjected to considerable review and re-evaluation from within the disabled people's movement and by disabled people (Crow 1996). Such discussion and analysis has been more and less supportive of the social model. It has questioned its capacity to address issues of difference in relation to gender, ethnicity, culture and sexuality (Walmsley and Downer, 1997; Gillespie-Sells et al. 1998; Vernon 1998; Goodley 2000). It has called into question the ability of the proponents of the social model

to address equally and to inter-relate its twin focus on (perceived) impairment and disability and on direct experience and social barriers. The social model of disability has been critiqued from feminist, cultural, postmodern and poststructural perspectives (Thomas 2002).

Thus it is important that any discussion as in this chapter that advances on the social model of disability from a different perspective must guard against approaching it with a simplistic understanding of the model. It is also helpful to remember that the social model did not originate with a concern to address the issues of mental health service users/survivors and therefore should not automatically be assumed to relate to it directly. There has been some confusion about this because of the lack of clarity and agreement about the definition of 'disabled' and 'disability' by disabled people and the disabled people's movement themselves. The terms have been used both narrowly to include people with physical and sensory impairments and more broadly to include a much wider range of groups, including mental health service users/survivors.

Issues of terminology

It may also be helpful at this stage in a volume whose focus is disability studies and the social model of disability, to say something about the language and definitions used in this chapter where the discussion concentrates on 'mental health' issues and mental health service users/ survivors.

There is as yet no agreement among mental health service users/survivors about terminology. It has become common for people with a mental illness diagnosis to be described as 'service users' or simply 'users' – certainly in the mental health field. But, in reality, the identity and naming of people included in this category is much more problematic, both to themselves and to others in

society. The proliferation of descriptions and self-descriptions in current use, for example - consumer, sufferer, service user, survivor, recipient, mad – is testimony to the uncertainties involved. Most of these terms, while familiar to mental health professionals, would not find easy recognition among non-professionals. On United Kingdom's streets currently, terms like 'mentally ill' and 'mental patient' would be more common and more easily understood. The description 'mad', repossessed and re-valued by some activists, would be widely understood as a negative term, seen by many as bordering on political incorrectness. But mental patient and ex-mental patient, characterizations from which many activists are seeking to escape, are likely to be viewed as realistic and acceptable by many people in broader society.

The two terms most often used by people actively involved in collective action are service user and survivor. Although they are often used simultaneously and are not always intended to have profound and contrasting meanings, service user and survivor are not the same term. At the very least, the term service user is neutral about the mental patient experience whereas the term survivor is taking a definite and critical position. Some commentators, building on this difference, have claimed that self-described service users are reformist while survivors are radical, even seeking the overthrow of a mental health service dominated by psychiatry. Whether or not this is true, it is clear that service user/survivor activists may have different priorities. Survivor, which has become shorthand for 'psychiatric system survivor', seeks to denote people's survival of mental health services rather than of 'mental illness'. It is often preferred to 'service user' because people reject the passivity denoted by that term and its tendency to define them primarily in terms of mental health services rather than their own independent qualities and characteristics. For some 'service users', however, the

term survivor is too aggressive and predictive. Because there is no agreement and all terms cause some offence, the term service user/survivor is used here in an attempt to be as inclusive and unpejorative as possible (Beresford and Campbell 2003).

Putting this discussion in context
To develop the discussion on madness, distress, research and a social model, it is helpful to make three initial connections. These are with:
- the recent history of mental health service user/survivor research;
- the mental health service user/survivor movement;
- the dominance of partnership approaches in the field of mental health service user involvement.

Each of these has important ramifications both for the development of the discussion and for understanding it.

Recent history of mental health service user/survivor research
In the context of disability research, research by mental health service user/survivor organisations and individual service user/researchers has been a late arrival. If we take 1997 as a reference point, at that stage there were barely any large-scale research projects and little contact with the broader disabled people's movement. Much research was small scale with limited or in some cases no funding. Service user/survivor researchers were generally working with very limited resources and little status or recognition. Furthermore there were relatively few such researchers and only a small number of service users/survivors with research training (Beresford and Wallcraft 1997).

Mental health service user/survivor movement

We can only make sense of mental health service users'/survivors' approaches to research (and as we shall see 'social models') through prior consideration of the mental health service user/survivor movement. There is both an old and modern history of service user/survivor organisations. During the eighteenth and nineteenth century there were examples of people (predominantly men), who were the equivalent of today's service users/survivors, who provided written accounts of their views and experience, calling for inquiries and reform. There were campaigning organisations like the Society for the Protection of Alleged Lunatics and the Alleged Lunatics' Friend Society (Porter 1987; Showalter 1987; Campbell 1996). Since the 1980s, there has been an enormous growth in the mental health service user/survivor movement. Many local and national organisations have developed. Some still question whether there is such a movement (Beresford and Campbell 2003), nonetheless, unprecedented numbers of service users/survivors have 'got involved'. Service user/survivor organisations have been contrasted with disabled people's organisations; the latter seen as being citizens rights based; the former as based on a consumerist approach (Barnes and Shardlow 1996; Barnes et al. 1999; Beresford 2000). Mental health service users/survivors and their organisations operate in a context of grossly inadequate and often inappropriate, unreliable and unsafe support services and arrangements and an increasing media and political emphasis on them as 'dangerous' and 'threatening' (Sayce 2000). This has been exacerbated by current government commitment to the extension of compulsory powers in new mental health legislation. This has overshadowed the activities of mental health service users/survivors. It has also significantly influenced resource allocation and diverted attention from the support needs of service users/survivors.

Dominance of partnership approaches, rather than separatism in 'mental health'

While there has tended to be some oversimplication in external accounts of the development of collective action by mental health service users/survivors, contrasted with that of disabled people, there have been some significant differences. These are relevant for understanding service user/survivor research and its relation with a social approach.

The emergence of the disabled people's movement has been characterised by:

1. the development of social approaches to disability;
2. the identification of strategies and goals following from the development of social understandings of disability;
3. the development of rights based approaches to disability consistent with such social approaches to disability;
4. the idea and practice of 'independent living' based on 'the social model'. This has led disabled people to prioritise the development of their own proactive approaches to support and change (rather than paying primary attention to the reform of traditional services) They have then sought to mainstream their own independent developments – notably through 'direct payment', self run assistance schemes and action based on anti-discrimination. (Campbell and Oliver 1996; Oliver 1996)

While it might not be appropriate to characterise the UK disabled people's movement as 'separatist', it has certainly deliberately developed its own agenda and for a long time has placed much more emphasis on independent development than partnership approaches. The process adopted by the mental health service user/survivor movement has been significantly different to this. It

has followed much more from a partnership model where:

- activity has mainly been concentrated in the mental health/psychiatric system with its structures and requirements for 'user involvement;
- there have been strong pressures for mental health service users'/survivors' involvement to be in mental health service based initiatives;
- most of the effort and energy of mental health service users who become involved has been focused on reforming traditional mental health services;
- much of the involvement of mental health service users has been related to the service, policy and practice system(s) rather than their own agendas;
- much of the funded activity of mental health service users/survivors has been in non-user controlled voluntary and statutory organisations.

Significantly, the best known campaigning and most radical of the national service user/survivor organisations established in the 1980s, Survivors Speak Out, experienced the most difficulties gaining and maintaining funding and in recent years has been very restricted in its profile and activities. More recently Mad Pride has emerged as a champion of direct action in the mental health service user/survivor movement. However, even they have sometimes felt constrained by the massive pressures and discriminations facing mental health service users. Pete Shaughnessy, one of its founders, writing in relation to the mental health alliance established to challenge the extension of compulsory 'treatment' beyond hospital, argued:

> We think that (mental health charities) are too soft and trying
> to pander to the Government and middle England…to show
> a united front we have limited our public attacks on Sane, and

saying Mind are a mixed bunch (Shaughnessy 2002).

Thus, while some mental health service users/survivors have taken a more radical and separatist position, developing their own initiatives rather than acting in partnership with professionals (O'Hagan 1993), this has not been the main thrust of activity. The approach advocated by the American survivor and activist, Judy Chamberlin, doing things 'On Our Own', has been the exception, rather than the rule in the UK (Chamberlin 1988).

The philosophical underpinnings of the mental health service user/survivor movement

There seem to be a set of shared values and beliefs underpinning the mental health service user/survivor movement. However, the movement does not seem to have developed explicit philosophies or theories comparable to those of the social model of disability or independent living developed by the disabled people's movement. The reasons for this appear to be various and complex. They seem to relate to two concerns which mental health service users/survivors seem to have. The first of these relates to challenging the underpinning medical model of 'mental illness' when service users'/survivors' intellects are inherently perceived as 'defective' or 'pathological' and the fear that rejecting a medicalised individual model of their situation and identity would lead to them being ruled out and discounted as simplistic and irrational (Campbell 1996). The second relates to service users/survivors worries about signing up to any kind of monolithic theory or set of principles for fear that these dominate and subordinate them and demand an orthodoxy in the same way as professional psychiatric thinking has done for so long. There is a strong libertarian strand in much mental health service user/survivor thinking.

Social approaches and mental health service users/survivors

There can be no question that the mental health service user/survivor movement and related groups and organisations are very conscious of 'the social' in their thinking and activities. Service user/survivor organisations have frequently been characterised by their twin emphasis on mutual aid/personal support and campaigning and action for broader (social and political) change. While as has been said, their activities have frequently had to focus on the (mental health) service system – because this is where they have been able to access resources – their concern has been much broader. The large and growing body of mental health service user/literature highlights an approach which is holistic and both crosses and goes beyond policy divisions. Service user/survivor discourses address both material and spiritual issues; the personal as well as the political. However, this still did not lead to the widespread development of any equivalent of the social model of disability.

It may be helpful at this point to restate the idea at the heart of the social model of disability, while reiterating that this has become the jumping off point for a wide range of critical discussions. The social model rejects the medicalised individual model that understands disability in terms of the deficiencies and incapacities occasioned by personal physical, sensory and intellectual impairment. Instead it asserts that the capacities of people with (perceived) impairment(s) are constrained and prejudiced by the creation and perpetuation of disabling physical and attitudinal 'barriers by the non-disabled majority' (Thomas 2002: 38). Thus disability is a form of social oppression and the social model highlights both social oppression and social understanding in relation to disability.

There is no doubt that most if not all mental health service users/survivors are well aware of the discrimination and oppression which they face, for example, as

parents, and in terms of negative stereotyping and their exclusion from employment. But this still has not led to any equivalent of the social model of disability playing a central role in their developing discussions or collective action.

Similarly, there is also a history of social approaches in the fields of psychiatry and 'mental health'. This can be traced to the post-war social psychiatrists and perhaps most significantly, the 'anti-psychiatrists', like Thomas Szasz and notably R.D. Laing and David Cooper. These certainly sought to move from traditional medicalised understandings, to social approaches, which explored social issues, for example, the role of the nuclear family in mental distress. (Laing 1965; Coppick and Hopton 2000). Michel Foucault also developed an influential critique of people's confinement and the emergence of medical psychiatry (Foucault 1967). However, while service users/survivors have sometimes found these helpful and in some cases, as having a contributory role to their own thinking and activities, the anti-psychiatrists came from a professional standpoint and service users played little or no part in the development of their ideas. Also they did not parallel or prefigure the concern with discrimination, social oppression and civil rights embodied in the social model of disability. The interest that some service users/survivors have had in these approaches can be seen as origins for the continuing alliances that have developed between them and organisations and groupings of radical professionals, like critical psychiatrists and critical psychologists. It is difficult, however, to see the social approaches of the anti-psychiatrists prefiguring any equivalent of the social model of disability. So while in one sense it can be said that social understandings have long played a part in the field of mental health and the thinking of mental health service users/survivors, they have not as yet developed to have a central role in the

development of a strategy, objectives or coherent philosophy for the service user/survivor movement.

Exploring the location of major service user/survivor research projects
There has been a considerable increase in funded service user/survivor led research in the last few years. Some highly visible and prestigious research activities have emerged. However, major mental health service user/survivor led research projects developing in the last few years have generally been based in non-user controlled organisations. Such organisations (which include the Sainsbury Centre for Mental Health, Mental Health Foundation, Institute of Psychiatry) are themselves generally based on a medicalised model of madness and distress. While some of these projects are internally run by service users/survivors, they face the stresses and tensions of being based in different kinds of organisations. This is in sharp contrast to initiatives from the disabled people's movement (for example, focusing on discrimination, user-led services, independent living, direct payments and the history of the disabled people's movement) which have either been based in organisations controlled by disabled people or undertaken by independent disabled researchers (Barnes 1991; Barnes, Morgan and Mercer 2001; Morris 1993). Viv Lindow has highlighted some of the issues facing 'partnership research':

> It is important to clarify different levels of survivor participation
> in research…Care must be taken, especially in partnership and
> user-focussed research that the process is not wittingly or
> unwittingly highjacked by the more powerful partner (Lindow
> 2001: 139).

Key examples of such large mental health service user/survivor projects are:

- The User-led Monitoring project (based at the Sainsbury Centre for Mental Health) which sought to measure and evaluate service users views of the nature and quality of mental health services. Mental health service users/survivors have developed interview schedules for use and adapt locally to monitor a range of mental health service settings. Local service users/survivors are trained as interviewers (Muijen 1998; Rose 2001).
- The two Strategies for Living three year programmes (based at the Mental Health Foundation) supporting and undertaking user led research locally and nationally. These have been managed by skilled and experienced service user/survivor researchers and were shaped from the start by service user/survivor researchers and broader consultation and involvement of mental health service users/survivors. This work has placed an emphasis on the coping strategies which survivors develop for themselves and on research and information-gathering to support service users' empowerment. It is currently supporting 15 local projects, as well as supporting the training of user researchers and has placed an emphasis on exploring complementary and alternative approaches to support as well as more holistic and spiritual approaches to madness and distress (Faulkner and Nicholls 1999; Faulkner and Layzell 2000; Nicholls 2001).
- The Service Users Research Enterprises (SURE) is an initiative based at the Institute of Psychiatry, King's College London, which has successfully bid for and undertaken major user led research projects. SURE is made up of a team of mental health service user/survivor researchers. Its activities so far include projects on 'consumer perspectives on ECT' (electro convulsive therapy), users and carers perspectives on continuity of care and a literature review on 'user involvement in change management in organisations funded by NHSE R & D SDO monies' (SURE 2002).

To the best of my knowledge, none of these initiatives has sought to base its activities explicitly on 'a social model of madness and distress', or explicitly and completely rejected traditional ('mental health') understandings and models. The 'social' has figured in their work. The Strategies for Living project in particular is based on a much more social approach than traditional 'mental health' research activities. Much (but not all) of the work of two of these initiatives can be seen, so far, to have been focused mainly on traditional service based approaches. Much good work is coming from these initiatives but they still raise worrying questions. The involvement of service users in non-user controlled research and development organisations may strengthen the latter's legitimacy and at a time when 'user involvement in research' is prioritised increase their capacity to secure research funding. However, it may actually make it more difficult for user controlled organisations to compete successfully on their own for such funding and therefore making if more difficult to advance service users' own research agenda and priorities. This needs to be monitored.

Mental health service user/survivor views of research priorities
In 2002, the Department of Health (DoH) undertook a strategic review of mental health research and development priorities. As part of this initiative they included two service users/survivors in the review group and set up a consultation meeting with a wider range of service users/survivors in response to their request. This provides an initial picture of service users'/survivors' views of appropriate research priorities in this field. These were in sharp contrast to existing DoH priorities that were narrowly focused on the psychiatric system and individual 'mental health'. Participants' proposals for priorities were very different to existing ones. These included:

A more holistic research approach.
Challenged the medicalisation of research and dominance of a medicalised individual model of 'mental health issues'.
Recognition of the importance of self management as a research focus.
A real focus on issues of race equality.
The importance of effective user involvement in the research process.

A conception of mental health research which was concerned with improving the overall wellbeing of service users and which took account of the wide range of policies, issues and considerations (such as social, economic, financial, employment related, housing and cultural).

Thus participants both highlighted the need for research to have a much more 'joined up' and social approach and for the exploration of alternative social approaches or models as a basis for research rather than prevailing medical models. This discussion represents an important and early explicit indicator of mental health service users'/survivors' and user researchers' interest in and commitment to a 'social model' (Department of Health 2002).

Towards social approaches in 'mental health' research
There is now the beginning of interest in the development of social approaches to understanding, which could provide a framework for survivor led research in the context of mental health. However this development is at a very early stage. In 2002-3, two conferences focusing on a social model of madness and distress were organised by Greater London Action on Disability. There was significant interest in these events from a wide range of service users/survivors. However over the same period, there has also been the development of a parallel

(professionalized) national discussion, convened by a new Social Perspectives Network. So far contributions to this discussion have mainly come from professionals and been based on an understanding of 'social' which seeks to take account of social factors in explanation rather than reflecting the rights based approach of the social model of disability. (Duggan et al. 2002) This network has also been publicly described (by the person in the Department of Health responsible for Mental Health Legislation generally and specifically for taking forward the new Mental Health Bill with extended provisions for compulsion) as:

> a network of professionals funded over two years to ensure a
> social care presence in the National Institute for Mental Health
> England (NIMHE) (Sieff 2003). This seems some distance from many
> service users'/survivors' understanding of a social approach.

What might a social model of madness and distress look like

While discussion is still at an early stage, some key issues have been highlighted (Beresford 2002). First there is an interest among service users/survivors in a social model which is located within a framework of the social model of disability, but which would also have transformatory implications for the social model of disability itself. It would highlight both issues of personal experience and social oppression. There is an unwillingness among many survivors to see 'impairment' as an objective part of their condition, so the discussion demands consideration of the socially constructed nature of 'impairment'. Such a model would also have to take account of the strong sense that many survivors have that their processing in the psychiatric system is related not only to them being seen as defective but also frequently dissident, non-conformist and different in their values from dominant societal values (Plumb 1994, 1999). These are all issues

that require further discussion among mental health service users/survivors.

Strategies for the future
A few years ago, two of us (Beresford and Wallcraft 1997) wrote that for the disabled people's movement the social model provided a starting point for thinking, strategy, and action. In contrast, for survivors it might be the other way round, as they came at a model to inform and increase the effectiveness of their activities much later. There are now renewed threats facing both social understandings of madness and distress and the rights of mental health service users. These notably relate to the emphasis on 'dangerousness' and demand for increased compulsory restriction of mental health service users/survivors rights. Second is a return in emphasis to the idea of 'recovery' which is likely greatly to reinforce medicalised understandings of service users' experience and situation.

One encouraging development has been the recent strengthening of contact, links and understandings between survivors and the disabled people's movement (Beresford, Harrison, Wilson 2002). This has been encouraged by further recognition of the shared aspects of their identity relating to the Disability Discrimination Act, the Disability Rights Commission, Human Rights Act and Direct Payments. All should be supportive of the reinforcement of interest and activity around a social model of madness and distress. It also seems important to explore the increased development of truly user-controlled research. It will be helpful to examine systematically both the barriers in the way of and possible supports for taking this forward. It is only likely to be through truly user/survivor controlled research that service users interests and agendas are effectively advanced. Moreover, the development of a social model is most likely to take place within this framework (as well as helping to take it forward). We can expect

that a social model of madness and distress will be as contentious and contested an idea as the social model of disability. This is certainly not a reason for seeing its development as anything but an urgent priority.

Bibliography

Barnes, C. 1991: *Disabled People in Britain and Discrimination.* London: Hurst and Co., in association with the British Council of Organisations of Disabled People. Barnes, C., Morgan, H. and Mercer, G. 2001: *Creating Independent Lives:*
An evaluation of services led by disabled people, Stage 3 Report. Leeds: Disability Press. Barnes, M. Harrison, S., Mort, M. and Shardlow, P. 1999: *Unequal Partners:*
User groups and community care. Bristol: The Policy Press.

Barnes, M. and Shardlow, P. 1996: Effective Consumers And Active Citizens: Strategies for users' influence on service and beyond. *Research, Policy and Planning,* 11 (1), 3-38.

Beresford, P. 2000: Review of: Barnes, M. et al. Unequal Partners: User groups and community care. *Disability and Society,* 15 (3), 540-542.

Beresford, P., Harrison, C. and Wilson, A. 2002: Mental Health, Service Users And Disability: Implications for future strategies. *Policy and Politics,* 30 (3), 387-396.

Beresford, P. 2002: Thinking About 'Mental Health': Towards a social model. *Journal of Mental Health,* 11 (6), 581-584.

Beresford, P and Campbell, C. 2003 forthcoming: Participation and Protest: Mental health service users /survivors. In G. Taylor and M. Todd (eds), *Democracy And Protest.* London: Merlin Press.

Beresford, P and Wallcraft, J: 1997: Psychiatric System Survivors and

Emancipatory Research: Issues, Overlaps and Differences. In C. Barnes and G. Mercer (eds), *Doing Disability Research.* Leeds: The Disability Press.

Campbell, J. and Oliver, M. 1996: *Disability Politics: Understanding our past, changing our future.* London: Routledge.

Campbell, P. 1996: The History of the User Movement in the United Kingdom. In T. Heller, J. Reynolds, R. Gomm, R. Muston, and S. Pattison (eds), *Mental Health Matters: A Reader.* Basingstoke: Macmillan in association with the Open University.

Chamberlin, J. 1988: *On Our Own: Patient controlled alternatives to the mental health system.* London: Mind.

Coppick, V. and Hopton, J. 2000: *Critical Perspectives On Mental Health,* London: Tavistock.

Corker, M. 1998: *Deaf and Disabled, Or Deafness Disabled?* Buckingham: Open University Press.

Crow, L. 1996: Renewing the Social Model of Disability, *Coalition,* July, 5-9.

Department of Health, 2002: *Report of the Service User Panel, Appendix 5, Strategic Reviews Of Research And Development – Mental Health Report Appendices.* Leeds: Department of Health.

Docherty, D., Hughes, R., Phillips, P., Corbett, D., Regan, B., Barber, A., Adams, M., Boxall, K., Kaplan, I. and Izzidien, S. 2003 forthcoming: This Is What We Think, *Disability Studies Quarterly.*

Duggan, M. with Cooper, A. and Foster, J. 2002: Modernising the Social Model in Mental Health: A Discussion Paper, Social Perspectives Network, Leeds: Training Organisation for the Personal Social Services.

Faulkner, A. and Layzell, S. 2000: *Strategies For Living: A report of user-led research into people's strategies for living with mental distress.* London: The Mental Health Foundation.

Faulkner, A. and Nicholls, V. 1999: *The DIY Guide To Survivor Research.* London: The Mental Health Foundation.

Foucault, M. 1967: *Madness and Civilisation.* London: Tavistock.

Gillespie-Sells, K., Hill, M. and Robbins, B. 1998: *She Dances To Different Dreams: Research into disabled women's sexuality.* London: King's Fund.

Goodley, D. 2000: *Self-Advocacy In The Lives Of People With Learning Difficulties.* Buckingham: Open University Press.

Laing, R.D. 1965: *The Divided Self.* Harmondsworth: Pelican.

Lindow, V. 2001: Survivor Research. In C.Newnes, G. Holmes and C. Dunn (eds), *This is Madness Too.* Ross on Wye: PCCS Books.

Morris, J. 1993: *Independent Lives? Community care and disabled people.* Basingstoke: Macmillan.

Morris, J. (ed.) 1996: *Encounters With Strangers: Feminism and disability.* London: Women's Press.

Muijen, M. 1998: Users Monitoring Mental Health Services, *Q-Net,* 6, 1.

Nicholls, V. 2001: *Doing Research Ourselves.* London: Mental Health Foundation.

O'Hagan, M. 1993: *Stopovers On My Way Home From Mars: A Winston Churchill Fellowship report on the psychiatric survivor movement in the USA, Britain and the Netherlands.* London: Survivors Speak Out.

Oliver, M. 1996: *Understanding Disability.* Basingstoke: Macmillan.

Porter, R, 1987: *A Social History of Madness: Stories of the Insane.* London: Weidenfeld and Nicolson.

Plumb, A. 1994: *Distress or Disability? A discussion document.* Manchester: Greater Manchester Coalition of Disabled People.

Plumb, A. 1999: New Mental Health Legislation: A lifesaver? Changing paradigm and practice, *Social Work Education,* 18 (4), 450-478.

Rose, D. 2001: *Users' Voices.* London: Sainsbury Centre for Mental Health.

Sayce, L. 2000: *From Psychiatric Patient to Citizen: Overcoming discrimination and social exclusion.* Basingstoke: Macmillan. Shaughnessy, P. 2002: On Community Treatment Orders (CTOs) And Injustice.

S.U.N. Newsletter, Manchester: Survivors' United Network, December: p. 2. Showalter, E. 1987: *The Female Malady: Women, madness and English culture 1830-1980.* London: Virago.

Sieff, A. 2003: The Mental Health Bill – The right prescription? Conference paper, Community Care Live, London: 21 May.

SURE. 2002: *Service User Research Enterprise, Annual Report, 2001-2002,* London: SURE, Health Service Research, Institute of Psychiatry.

Thomas, C. 2002: Disability Theory: Key ideas, issues and theories. In C. Barnes, M. Oliver, and L. Barton (eds), *Disability Studies Today.* Cambridge: Polity Press.

Vernon, A. 1998: Multiple Oppression and the Disabled People's Movement. In T. Shakespeare (ed.), *The Disability Reader: Social science perspectives.* London: Cassell.

Walmsley, J. and Downer, J. 1997: Shouting the Loudest: Self-advocacy, power and diversity. In P. Ramcharan, G. Roberts, G. Grant, G. and J. Borland (eds), *Empowerment In Everyday Life: Learning Disability.* London: Jessica Kingsley.