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Psychiatric System Survivors and Emancipatory research: Issues, overlaps and differences

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To approach emancipatory research in the survivors' movement, it is helpful first to have an understanding of the relation of the movement to disability and the disabled people's movement, as well as an understanding of the survivors' movement itself and of the issues facing survivors. We begin with the relation between survivors and disability and the disabled people's movement.

THE SAME BUT DIFFERENT

The relations between survivors and disability and between the survivors' and disabled people's movements are complex and there is little agreement about them. For example, there was only one mention of survivors in Jane Campbell and Mike Oliver's major examination of disability politics and the only organisation referred to is an organisation for mental health service users (Campbell and Oliver, 1996). Jenny Morris's exploration of feminism and disability on the other hand, included a chapter by a woman survivor, highlighting the links with disability and the disabled people's movement (McNamara, 1996). Some disabled people do not see survivors as disabled, because they do not have an impairment or their situation may not be permanent, while others do. Some survivors do not see themselves as disabled because they associate disability with the medicalisation of their distress. There are also fears and anxieties among survivors and disabled people about being associated with the negatives linked with the other group.

There are also important overlaps between the two groups. Some survivors also have physical or sensory impairments, often related to the chemical and other damaging 'treatments' like ECT, which they have experienced. Some people with impairments and with learning difficulties also have experience as survivors which may be linked with the way they have been treated as disabled people.

There are many similarities in how disabled people and survivors are treated in society. Both have their experience subjected to medical interpretation and 'treatment'. Both face social oppression and discrimination. As a result, both face disproportionate problems of poverty, unemployment, social and economic insecurity. Many survivors are included as 'disabled people' in the medical definitions upon which eligibility to disability benefits and services is based. Survivors are also included in the medically-based Disability Discrimination Act and some survivors are eligible to run their own personal assistance schemes under the Direct Payments Act.

There are also links and overlaps between the two movements. Some people involved in the survivors' movement are also involved in the disabled people's movement. Survivors were involved in the campaign for civil rights legislation. The British Council of Disabled People struggled successfully alongside Survivors Speak Out to gain the inclusion of survivors in direct payment legislation (Beresford, Gifford and Harrison, 1996).

THE PHILOSOPHY OF THE SURVIVORS' MOVEMENT

The survivors' and disabled people's movements are very different, yet also have important similarities. So far, most emphasis has been placed on the differences. Yet there is one difference which it is important to explore. This concerns the philosophies of the two movements.

The social model of disability, developed by the disabled people's movement, has provided a dynamic and developing conceptual framework which has been both liberating for individual disabled people and a basis for coherent and effective collective action and strategies. It underpins the commitment of the disabled people's movement to civil and human rights, its stress on self-organisation and the goals of independent living, social inclusion and anti-discrimination. It has also provided a framework for the emancipatory research of the disabled people's movement as well as being a subject of such research.

The survivors' movement does not have an equivalent of the social model. While some survivors have found the social model of disability helpful because of its stress on social oppression and discrimination, others reject it for themselves, because they do not see themselves as having any kind of impairment. They interpret their madness or distress in terms of different understanding, experience or perceptions, rather than as an impairment. The social model of disability, therefore, cannot simply be

transposed to the survivors' movement, although some disabled commentators, in an effort to be inclusive, have done this.

The survivors' movement therefore does not have a clear philosophy of its own. This has long been seen by many of its members as one of its strengths and attractions. It has had the appeal of being a broad church, where people of very different experience, background, education and politics, could co-exist. Survivors Speak Out, for example, includes people who are opposed to demonstrations and direct action, as well as others who take part in them, both as survivors and as disabled people. There has been no pressure to conform to a particular belief system.

This does not mean that the movement is not informed by values and ideals. Where there has been a strong sense of agreement is that survivors should be treated with respect and have the right to speak for themselves. Involvement in the movement brings with it a strong sense of self-worth and shared experience and understanding. Survivors know that in the movement, psychiatric judgements on and interpretations of them do not rule. In this sense there is a challenge to the dominant ideology, but so far it has not developed into a shared alternative analysis and vision of distress.

It is not clear why the movement has developed in this way. It may be because of survivors' fears of replacing one rigid belief system, embodied in the medicalisation of madness and distress by the psychiatric system, with another, or of dividing rather than uniting survivors. One reason, which Peter Campbell identifies, is the concern about further reducing survivors' chances of gaining 'a decent hearing for their proposals' (Campbell, 1996a: 221). Thus while some founding members of the survivors' movement were either in contact with or sympathetic to the anti-psychiatry movement of the 1960s and 1970s, this should not be taken to mean that the movement is particularly informed by or reflects an anti-psychiatry position. Furthermore as Peter Campbell says:

' "Anti-psychiatry" has become a slogan that is routinely used by traditional mental health workers to denigrate and dismiss ideas that threaten their expert world-view and status' (Campbell, 1996a: 221).

The power of the psychiatric establishment and its influence on broader social values and understanding cannot be overstated. It has had a profound effect on the identity of survivors/mental health service users. While part of the dominant message about mental distress is that 'it can

happen to anyone', the powerful subtext is that to use or have used mental health services or to experience mental distress is to have a fundamentally spoiled identity. This has many expressions at both individual and collective levels. It means that many mental health service users find it very difficult if not impossible to feel proud of who they are and do not see their situation as comparable with that of people with impairments. For them, this might seem almost like another manifestation of their madness. They can certainly expect it to be interpreted as such by the psychiatric system.

This expectation also means that many activists feel closely circumscribed in what they can do. They expect their views and analysis to be dismissed and attacked as extreme and symptomatic of their defective understanding, reason and intellect. Similarly, many fear that if they take direct action along the innovatory lines of the disabled people's movement, this will be seen as further evidence of their irrationality and madness and receive an aggressive and regulatory response.

Thus the survivors' movement's lack of a distinct and coherent philosophy may be traced to its desire to be inclusive and minimise conflict within, as well as a concern to limit attack from outside. We can also add to this the difficulties which the movement has had developing a philosophy because of the practical problems of very limited resources and restricted opportunities for survivors to get together to develop their thinking collectively. However the hole created by this lack of agreed and coherent philosophy has not remained unfilled. Instead at least two sets of ideas from the dominant ideology have moved in to occupy the space. These are the concepts of mental illness and consumerism. Both have important implications for the survivors' movement and research associated with it and both have added to the uncertainty and ambiguity of its thinking and activities.

Some members of the survivors' movement, including the authors, reject a medical model of madness and distress. They see it as intellectually unsustainable and deeply damaging to the people to whom it is attached. It is the equivalent of the individual medicalised model of disability. They reject the ideology of mental illness, as inextricably associated with pathology and inconsistent with securing the rights and needs of people experiencing madness or distress. The construct of 'mental illness' is a part of a modernist project which devalues the diversity of human experience and perceptions and is preoccupied with analysis, eradication, physicality and mechanical and chemical constraint, rather than

understanding, empathy, support and an holistic approach to the body and self.

For many other members of the movement and many more users of mental health services generally, however, the idea of 'mental illness' is internalised. This is as a result of their broader socialisation and passage through the psychiatric system. It is also likely to be the only analytical framework with which they are familiar for understanding their situation, feelings and perceptions. The survivors' movement, including organisations like Survivors Speak Out, aware that its membership includes both people who reject and accept a medical model, has not adopted a clear position on the issue, to enable the two groups to continue in broad alliance.

The second key concept which has entered the survivors' movement is that of *consumerism*. Consumerism has emerged as a key idea in current health and welfare because of the broader shift to the political right and to the private market in the UK and its association with a new interest in 'consumer choice', 'user involvement' and 'needs-led' services. This interest in the individual service user as 'customer' and 'consumer' undoubtedly served as a major impetus and legitimation for the UK mental health service users/survivors' movement. Certainly survivors involved in developing the movement saw it as an opportunity to be used. Comparing mental health service users' and disabled people's groups, Marian Barnes and Polly Shardlow, distinguish between the strategies of the former which they see as based on 'consumerism' and of the latter, based on 'citizenship' (Barnes and Shardlow, 1996a). But this raises a key point about the survivors' movement's use of consumerist ideas and rhetoric. These have frequently been adopted uncritically as symbols of a new determination to speak and act for themselves by individuals and groups who are not necessarily familiar with their ideological associations. It may be not be helpful or advisable to take their use at face value.

The indebtedness of the survivors' movement for what philosophy it has to exterior, dominant institutions and ideologies, is not only the result of its limited development of its own philosophy. It is also closely related to the nature of its relation with the mental health service system. The UK disabled people's movement has largely developed independently of disability professionals and the disability service system. It has placed an emphasis on developing organisations of disabled people and challenging the traditional dominance of organisations for disabled people. In the US, there is a strong tradition of separatism in the survivors' movement, most

notably reflected in the work of Judi Chamberlin and her pioneering book, *On Our Own* (Chamberlin, 1988). But there is also another wing to the US movement which is more closely associated with the mental health system and dominant values.

THE SURVIVORS' MOVEMENT AND THE MENTAL HEALTH SYSTEM

In the UK, the survivors' movement has been closely linked with the mental health service system in two important ways. First, many of its activities have been based in the system; establishing self-advocacy groups and patients' councils within services and seeking to reform the service system. Second, much of its work has been undertaken in close association with professional 'allies' and through organisations for mental health service users. The dominant way of working has been co-operation rather than separatism. The organisations with which it has worked, many of which have been involved in service provision, as well as in campaigning, advocacy and research, have generally rested on a medical model of madness and distress. Conventional fudges, which some have adopted, like MIND's, talking about 'mental health' and 'people with mental health problems', rather than 'mental illness' do not separate it from the psychiatric system, nor offer either an intellectual or political way forward.

The survivors' movement's relation with the service system and these organisations is complex and ambiguous. It is linked with the movement's continuing reliance on these organisations for funding, employment and legitimisation. To maintain relationships with them, therefore, there have been strong pressures to fudge the movement's philosophy, for both individual activists as well as the movement more generally.

The reading which we offer here of the development of the survivor's movement is one which highlights caution, collaboration and a desire to minimise conflict. What has been the result? This seems to be a movement which is fragmented, vulnerable and, as we have said, without a clear and agreed philosophical base. While, for example, the disabled people's movement has established one national umbrella organisation controlled by disabled people and their organisations, in the survivors' movement, there are several, including Survivors Speak Out, the United Kingdom Advocacy Network and MindLink. MindLink, which is perhaps the best resourced of the three, is linked with an organisation for mental health service users that is regarded with increasing caution by many members of the survivors' movement (Anonymous, 1996).

Money and resources are still concentrated in organisations for rather than controlled by survivors. For example, MIND has received £1 million to distribute as the MIND Millennium Award Scheme and the Mental Health Foundation, another organisation for mental health service users, has received a lottery grant of more than £500,000 to undertake a user-led research study of alternative and complementary treatments. Meanwhile Survivors Speak Out has very limited funding and one part-time worker. Much of the research undertaken by survivors has been carried out under the auspices of non user-led organisations, raising issues of ownership and control.

When the disabled people's movement sought civil rights legislation, it produced its own detailed study as a basis for its own campaigning (Barnes, 1991). MIND, the organisation for mental health service users, published a short pamphlet as the basis for its anti-discrimination campaign, jointly written by a survivor and its head of media relations (Read and Baker, 1996). Another research study by a survivor, Diana Rose, highlighted the discrimination mental health service users could expect 'in the community', but again it was produced within a non-user led organisation (Rose 1996).

Despite the efforts of the survivors' movement to collaborate, significant divisions remain. For instance, a new Open University Course Mental health and distress: perspectives and practice is linked with an anthology of writings by people who have experienced mental distress (Read and Reynolds, 1996), and a reader 'by acknowledged experts in the mental health field', which is described as 'challenging traditional understandings of mental health, emphasising the perspective of mental health service users' (cover blurb). Yet only one of its 53 contributors writes from the perspective of the survivors' movement (Heller, Reynolds, Gomm, Muston and Pattison, 1996). As far as the dominant debate is concerned, survivors and the survivors' movement still seem to be seen primarily as a source of experiential data, rather than creators of our own analysis and theory.

FROM INVOLVEMENT TO EXCLUSION

Two related developments are currently causing some members of the survivors' movement to take stock of their position and the future of the movement. These are first, their participation in service system initiatives for consultation and 'user-involvement', and second, the increasing

association of mental health service users with dangerousness and violence. We begin with the first of these.

Survivors have invested a lot of time, effort, emotional energy, commitment and trust in agency-led schemes for user-involvement. This has also been linked with the movement's particular focus on reforming the service system and working in partnership with professionals. In recent times, however, there has been a growing sense of disillusion with this reactive strategy, particularly among experienced members of the movement and concerns that it may actually be adding to survivors' disempowerment. While, of course there have been exceptions, in general the results seem to have been very limited. In this, survivors' experience has been similar to that of the disabled people's movement (Bewley and Glendinning 1994). However a difference between the two movements has been the extent of survivors' investment in such activities. The disabled people's movement has devoted much more of its energy and resources to its own broader campaigns independent of the service system, for example for civil and human rights, accessible 'public' transport and challenging the traditional imagery and activities of charities for disabled people. One expression of the survivors' movement's rising dissatisfaction with conventional initiatives for 'user-involvement', is a growing interest in increasing the control which individual survivors have in their contact with the psychiatric system (e.g. Leader, 1995).

The increasing association of mental health service users with violence and dangerousness has, like the introduction of schemes for user-involvement, been closely associated with the 1990s community care reforms. While the catalogue of tragedies, murders and suicides associated with mental health service users, particularly people labelled as schizophrenic, have been linked in official enquiries with the failure to provide adequate and appropriate support, its political and media presentation has been in terms of the threat from service users. They are represented as threatening, irrational and unpredictable. There has been an increasing emphasis on them as, 'other'. The dominant media image has been of staring black faces and headlines like: 'Nightmare In the Community' (Palmer 1997).

While the tragedies have been linked less with people discharged from longstay institutions than with 'revolving door patients' left unsupported, the dominant pressure group and media demand has been for the reinstitutionalisation of 'mental patients'. There has been cross-party political consensus that more restrictions should be imposed on mental

health service users. Labour spokespersons are as likely as Conservatives to say that:

'there must be proper supervision... We need a new Mental Health Act that provides proper powers for the care of seriously ill people' (Jowell, 1997).

As well as demands for the reincarceration of mental health service users, they are now subject to new restrictions in their own homes. The demonisation of mental health service users and the emphasis on their 'otherness', has also meant a shift of resources from supporting people in distress to regulating people stereotyped as a public or political threat. Survivors' organisations have been able to play very little part in this discussion.

The political and social climate for both survivors and the survivors' movement has if anything deteriorated during the 1990s. As Peter Campbell has said:

'Outside the mental health services and despite the good work of user/survivor action groups, current or former mental health service users are held in little higher regard now than they were in 1983 (the year of the Mental Health Act). Arguably, they are now more likely to be seen as dangerous and inferior' (Campbell, 1996a: 224).

THE DENIAL OF SURVIVORS' RIGHTS

This leads us to another important distinction to draw between the situation of survivors and disabled people. The disabled people's movement has campaigned against the arbitrary abuse of disabled people's human and civil rights. The restriction of survivors' rights, however, is enshrined in law as part of the provisions established to maintain and 'treat' them. Denial of rights is not presented as an aberration in the treatment of survivors, but as necessary and legitimate. While the public debate about disabled people has increasingly been about the need for their inclusion in society, that about survivors has been about the need to exclude them.

While the survivors' movement would not disagree that survivors may sometimes need security and asylum to safeguard both their own rights and those of other people, they would draw a clear distinction between this and the way in which they are actually treated by the psychiatric and

criminal justice system, where their rights are routinely restricted and dangerous treatment imposed forcibly and routinely without adequate safeguards or redress. Much less attention has been paid to the mental health service users who have died within the psychiatric system in worrying circumstances than to the smaller number who have harmed others.

THE CONTEXT OF SURVIVORS' RESEARCH

It may be helpful at this point to sum up the context of emancipatory research in the survivors' movement. It is a context of:

- the dominance of organisations for survivors and survivors' unequal relationship with them;
- a political, media and social climate which is increasingly hostile to survivors;
- the continuing dominance of the psychiatric profession and system;
- the association of distress with spoiled identity and defective understanding; and
- the survivor movement's lack of a coherent and agreed philosophy.

Despite these difficulties, indeed in some cases, perhaps because of them, there has been a significant development of emancipatory research in the survivors' movement. It has not always been conceived of as 'emancipatory' research. It has also been understood as 'user-led' research, with an emphasis on survivors themselves undertaking research. But while it has its distinct identity and history and has developed separately, it also has much in common with the emancipatory research of the disabled people's movement. There have also been research collaborations with different movements, including the disabled people's movement, like, for example, the research project led by Viv Lindow analysing the National User Involvement Project (Lindow, 1996). Undertaking emancipatory research has been part of the survivors' movement's project of survivors speaking and acting for themselves; improving their lives and liberating themselves from an oppressive psychiatric system; of changing and equalising relationships between research and research subjects, and developing survivors' own knowledge collectively.

It has also represented a revulsion from traditional research on survivors, not least medicalised and drug company research which objectified and pathologised mental health service users. Mike Lawson, founding member of Survivors Speak Out talked of invasive research which was

'psychiatric pornography' (Lawson, 1988). More recently Ann Davis has referred to the way in which mental health research continues to 'use' mental health service users (Davis, 1992). For many mental health service users, the researcher has represented another psychiatric professional with power over them (Wallcraft, 1997).

More subtle processes of restructuring and incorporation are still taking place in mainstream research on survivors. For example, Ann Rogers and David Pilgrim, in their study of a service users' organisations imposed their own interpretations on their activities and their own conceptualisation of the movement as a 'new social movement' (Rogers and Pilgrim, 1991). Marian Barnes and Polly Shardlow in their examination of survivors/mental health service users' own perceptions of their identity, pre-empted their conceptualisation by defining them as 'people with mental health problems' and 'mental health user groups' (Barnes and Shardlow, 1996b).

Emancipatory research associated with the survivors' movement has developed in different ways and from different bases. These include:

1. Survivors acting as paid and unpaid consultants and researchers for non- statutory and statutory mental health organisations

The Sainsbury Centre for Mental Health developed a long-term co-research relationship with a group of psychiatric service users. The group acted as consultants to research into community mental health services, produced their own report and then three members carried out a user evaluation of a case management project. The Centre provided support in designing and undertaking the project and published the final report, while the user- researchers maintained final editorial control. In their report, they set out their case for user-led research:

'It was strongly believed that users, who can demonstrate their common experience with other users, could get at the truth much better because they could persuade others of their independence from the service...In particular the issue of independence from the service provider is very difficult for non-user researchers. Their background, presentation and links with service agencies make it difficult for users to believe that their views will not get back to those who provide the service directly. They then fear that their service might be withdrawn or that they will be made to suffer for their criticism... The perceptions that (user-led research) seeks are those that users

would want to tell each other, not what they have been told is good for them' (Beeforth, Conlan and Graley, 1994: 4).

A second example is the Mental Health Task Force User Group made up of nine current and former mental health service users representing the three main user organisations in England, which was commissioned to carry out 'consumer satisfaction research'. The Mental Health Task Force was an executive group set up for two years by the Department of Health to investigate the closure of large psychiatric hospitals and the transfer of services 'to the community'. A small working group of the user group, of whom one of the present authors was a member (JW), identified a set of rights and principles on which mental health service users wanted services to be based, for local application, based on research with local and national user organisations and agreed by service users more widely (Mental Health Task Force User Group, 1994).

2. Research produced by conferences of service users

An example of this approach, which has frequently been used in survivor-led research, is the report and manifesto which resulted from the 1992 Mid- Glamorgan Mental Health Service Users' Conference. This called for major changes in services to provide the services which mental health service users wanted, for example, crisis support services, in which they had more control; as well as restrictions on 'treatment' which people experienced as oppressive, including the use of ECT, major and minor tranquillisers and negative staff attitudes. One of the key issues raised was discrimination against women in the psychiatric system:

'Doctors (often men) contribute to why women feel bad by assuming or implying that a woman's problem or distress has physical causes, such as her appearance, hormones or PMT.

Male doctors don't or can't listen, so they prescribe drugs.

Once you have been labelled "mentally ill", doctors use it as an excuse not to have to listen to you.

Many of the women who attended the conference had had ECT. They had been told things like, "It will help you to forget the past" -if they had been told anything at all. Women were not told about the side-effects of ECT' (Mid- Glamorgan Association of Voluntary Organisations, 1992: 51-2).

3. Funded research by survivors

An important example of such funded research is Mary O'Hagan's report of her study visits, supported by a Churchill Fellowship, visiting survivor organisations in the US, UK and the Netherlands. Her work was aimed primarily for a readership of psychiatric survivors. She made her personal and ideological position clear and offered her research as a contribution to the movement for survivor-led services, warning against the danger of 'mimicking' existing services, social relations and structures. She talked about the need for the survivor movement to link experience with ideology and ideology with practice, saying:

'looking back, this report is the working and reworking of two themes. The first theme can be condensed into the word "meaning". What is the meaning of our madness? How does this meaning contribute to the ideology of our movement? The second theme is "management". How do we manage our activities so they will truly reflect our ideology' (O'Hagan, 1994: 95).

4. Unfunded research by survivors

An important example of such unfunded research is a survey of 85 mental health service users, at home and in hospital, undertaken by Janet Cresswell, a long-term patient in Broadmoor special hospital. Half her sample talked of the negative effects of treatment, like addiction to tranquillisers:

'Further problems to the ones for which help was originally sought were experienced by over half the users. The suffering of many users under the heading of "medical treatment" is an indictment of the medical profession' (Cresswell, 1993).

Survivor-led research challenges psychiatric orthodoxy which has traditionally emphasised professional boundaries, scientific objectivity, technological solutions to emotional problems, treatments with quick 'results', standardisation of diagnosis and treatment, clinical settings and the central role of the medically trained psychiatrist. Some of the ways in which survivor research challenges the medical paradigm, either subtly or overtly are that:

- the concept of 'crisis' or distress is often preferred to the concept of 'mental illness';
- social or spiritual models of understanding distress are proposed rather than medical ones;
- hearing voices and other devalued perceptions and experiences are seen as phenomena with a number of possible explanations, rather than as a prime symptom of 'psychotic illness' (Romme and Escher, 1993);
- psychiatric treatments are sometimes described as abuse or torture, rather than medical treatment; and
- medical concepts and language and psychiatric labels are often regarded as damaging, stigmatising, unhelpful and inappropriate.

CHANGING THE SYSTEM

As we have seen, much survivor research has focused on the service system and people's experience of it and has frequently been based within the system itself. It includes evaluation of services as well as surveys of service users' views. (e.g. Wallcraft, 1993; North East Essex Service User Development Group, 1993). But such emancipatory research seeking to bring about change in the service system frequently runs into major difficulties. There are problems of restricted access and dissemination and of massive resistance to making change when its findings are negative and uncomfortable for service providers, as frequently they are. Mary Nettle (1996) has reported just such an experience in detail. But this draws us to one of the key dilemmas facing the survivors' movement and survivor-led research. The psychiatric service system is unpromising ground for reform, but many survivors are held within it. It cannot be ignored. Louise Pembroke, of *Survivors Speak Out*, has talked of some of the continuing dilemmas and contradictions which this poses for survivors as both activists and researchers:

'I want to make things better for people in the psychiatric system but I also want to demolish it. There are dangers in collaboration, but there are positive things too, like patients' councils where we can at least help people gain their voice before leaving the bin' (quoted in Croft and Beresford, 1991: 72).

Sharp differences between survivor-led research and that carried out by mental health professionals are often revealed in the choice of starting point, subject matter and perspective. While psychiatric researchers

generally evaluate existing orthodox psychiatric interventions from an assumption that mental illness can be clinically defined, survivor-led research often treats the concept of mental illness as open to question. While the findings of orthodox research generally point to incremental changes within the existing paradigm, user-led research posits more radical shifts of control, rights, knowledge and resources to service users and their organisations. It indicates the need to replace the dominant biochemical and genetic research paradigms, with more open, equal and holistic approaches. This has led to an increasing interest in and focus on alternatives, to both existing ideas and services.

SURVIVOR RESEARCH ON ALTERNATIVES

Emancipatory research in the survivors' movement is most developed where it focuses on alternatives. This extends to exploring alternative therapies, systems of support and interpretations and analysis of people's experience and perceptions. It will be helpful to examine some of the key examples of such survivor-led enquiry. First is the work on eating distress and self-harm in which Louise Pembroke has been centrally involved. Here we see the reconceptualisation of two key expressions of distress. In both cases, the process of enquiry is one which begins with developing and exchanging people's first hand accounts of their experience, extending survivors' own knowledge, challenging traditional paradigms and value judgements and developing new interpretations and new language. We move from 'eating disorder' to eating distress; from 'self-mutilation', 'self-destructive' and 'para-suicidal' behaviour to self-harm. It is a process which leads to and is directly connected with action and change, through bringing people together, setting up networks and organisations and working for change, both through collaboration with the service system and through pressing for change through collective action (Pembroke, 1992; 1995).

In the discussion of eating distress, for example, there are personal insights into the social pressures which lead to eating problems; how it feels to have an eating problem and the frequent insensitivity of psychiatric services to the realities of people's lives and emotions. As one woman said:

'Whatever way I expressed my distress or dissent it was declared invalid, stupid or sick. The so-called eating disorder label is an inadequate explanation of the very complex reactions and feelings I experience. Indeed for me it is a simplification of an expression of distress which clearly

demonstrates the need for cultural and social change... I feel that people labelled as mentally ill experience and express feelings the majority do not allow or open themselves to... What I am is a woman who discovered at an early age that a woman's worth in our society is based upon her appearance' {Pembroke, 1992:19).

Another expression of this development in survivor research is Vivien Lindow's Joseph Rowntree Foundation supported study of self-help alternatives to mental health services. Against the odds of inadequate funding and support, the survivors' movement is beginning to develop alternatives to existing services, from asylums and sanctuaries, advice and counselling services and personal assistance schemes, to training courses, employment schemes and complementary therapies, as well as offering their own visions of the kind of support they want (Campbell, 1996b; Read, 1996). Vivien Lindow explores some of the initiatives that have already emerged in the UK and elsewhere and identifies the ideas and principles underpinning them as a basis for future development of user-led alternatives and the increased commissioning of such schemes (Lindow, 1994a; 1994b).

Another survivor, Brenda Alexander, carried out a small-scale study of survivors' experience of alternative therapies, particularly aromatherapy. She concluded:

'The abuse of power personified in the control and management of some individuals coping with a "disorientated" mind and body are only reinforcing low esteem and adding to their problems. A continuing partnership between professionals and users on a more holistic, informed choice and consent basis is indicated by my research. The "medication culture" must be re-evaluated in the nineties' (Alexander, 1993).

TOWARDS A SOCIAL MODEL OF MADNESS AND DISTRESS

Survivors' interest in alternatives and their emancipatory research exploring it, point to some of the most hopeful ways forward both for the movement and for individual mental health service users. There seems to be some truth in the generalisation that the social model of disability has provided a helpful framework giving purpose and direction to the emancipatory research emerging from the disabled people's movement. In the survivors' movement, the developments seem to be the other way round. The growing body of emancipatory research being undertaken by

survivors is beginning to point to a clearer philosophical basis for the movement. There is a growing recognition from within that the movement needs to develop its own philosophy. In a recent history of the UK survivors' movement, Peter Campbell, one of the movement's founding members concludes:

'One of the major challenges of the next few years may be to find a coherent overall philosophy that can integrate a clearer range of focuses' (Campbell, 1996a: 224).

The nature of such a philosophy is beginning to be clearer, although as yet there is no clear consensus about it (Beresford, 1997) .We can expect such a philosophy to be based on a social model of madness and distress. The issues that this is likely to highlight include:

- the social causes of our madness and distress;
- the medicalisation of our experience and distress;
- the destructive and discriminatory response to it from both psychiatry and broader society;
- the need for a social response to the distress and disablement which survivors experience, addressing the social origins and relations of their distress, instead of being restricted to people's individual difficulties; and
- the need for survivor-led alternatives to prevent distress and offer appropriate support for survivors (Beresford, Gifford and Harrison, 1996).

Emancipatory research by survivors will have a key role to play in both exploring these issues and in developing and disseminating such a social model of madness and distress.

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