Distress or Disability?

Proceedings of a symposium held at Lancaster University

15-16 November 2011

Edited by Jill Anderson, Bob Sapey and Helen Spandler

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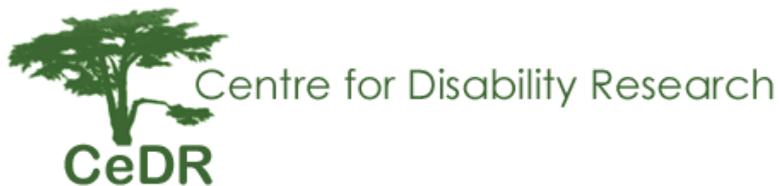
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Introduction

Jill Anderson, Bob Sapey and Helen Spandler

This symposium was organized jointly by Mental Health in Higher Education, the Centre for Disability Research at Lancaster University and the School of Social Work at the University of Central Lancashire. The symposium was by invitation only and brought together scholars (including academics, activists and research students) from the north-west of England to explore the issues that arise from trying to situate mental distress or 'madness' within the social model of disability. We specifically focussed on psychosis, hearing voices and other extra-ordinary experiences as these raise particular issues and challenges.

While there is a long history of thinking, activism and writing about the links between mental health and disability activism, difficulties remain in terms of how they can, and if they should, be brought together. Disability studies developed out of the disabled people's movement, focusing on the relationship disabled people have with society. The social model of disability which has dominated UK disability studies has been primarily concerned with the disadvantages people face because of social responses to impairment. While stigma and disadvantage are also important issues in mental health, critical work in this field tended to focus on re-conceptualising the experience of madness or distress itself and its social causes. As a result, activism has usually focused upon the relationship people experiencing distress have with mental health services, professionals as well as the wider social systems in which they are located. To some extent this is in contrast to disability activism where disability and impairment issues are often distinguished in order to focus on the former. Further, many people experiencing mental distress would reject the label of 'disabled' as it is considered stigmatizing, whereas for disabled people this is a reclaimed term that offers a positive identity.

In 1994 Anne Plumb wrote a discussion document for the Greater Manchester Coalition of Disabled People called *Distress or Disability*? In this important paper which is reproduced in this e-Book, she argued for the autonomy of mental health system survivor activism and highlighted some of the difficulties of integrating mental distress within broader disability politics. We asked participants to build on her ideas and to develop some thinking on these issues. We also suggested participants read Peter Beresford, Mary Nettles and Rebecca Perring's recently completed study funded by the Joseph Rowntree Foundation, *Towards a social model of madness and distress? Exploring what service users say*.

Additionally we drew on the work of others in the north-west. Carol Thomas (Lancaster University) has made a significant contribution to the theorizing of disability through her proposition for an extended social-relational model of disability which incorporates impairment effects and the psycho-emotional effects of disability. We explored the possible implications of the idea of 'psycho-emotional disablement' in the context of mental health. In addition, Helen Spandler (Uclan) has challenged the social responses to psychosis which deny people the right to experience their distress and to receive support that they choose as appropriate to help them do so. The recent promotion of recovery, social inclusion and personalisation in mental health has been based, at least in part, on a social model of disability and related ideas from the independent living movement. If this is the case, then its applicability to madness/distress has profound implications for practice. As such, we hoped to consider the implications of these issues for mental health practice, education and activism.

This e-Book draws together the papers presented at the symposium. It seeks to collate and disseminate ideas that were shared. What is harder to capture is the experience of an event such as this; for it is in its interstices - its dialogue and encounters - that its essence lies. We sought, in shaping the two days, to maximise opportunities for connection, through insisting on short presentations and prioritising discussion time. Papers were submitted, circulated and read in

advance; requiring a measure of discipline and proactive engagement from all those involved. They were placed, within the programme, in relationship to one another. Some practices evolved at the event itself. For example, divesting ourselves of flipchart paper, we solicited no formal feedback from small group discussions. This resulted, for some, in a sense of feeling freed up and allowed discussion to flow. We are grateful to all who contributed to the symposium, and to this publication, including those who have reflected on its process in these pages.

part one

...distress or disability?

A discussion document by Anne Plumb

(February 1994)

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...distress or disability?

Anne Plumb

The Medicalisation of Distress and Dissent

> 'We support a definition of disability that encompasses people with a physical, sensory, intellectual, psychological, emotional or any other *hidden impairment* and, therefore, includes people with learning difficulties, system survivors, cancer and those with HIV/AIDs.' (my *italics*).

This support is given by the Southampton Centre for Independent Living in an advertisement for a job of Disability Training Administrator/DET (Disability Equality Training) Trainer in 1993.

I am one of the people this definition encompasses. I am a system survivor; I belong to an organisation called Survivors Speak Out (SSO). In our constitution survivors are defined as 'people who receive or have received 'mental health' services'. On the face of this, we would seem to have, or have had, something wrong with us medically (to be less than healthy?). However, this definition is more carefully worded than it might at first appear. To *'receive a service'* does not necessarily mean that we agree with it, especially if this 'service' is inappropriate, unasked for, or damaging, and where treatment can be imposed without consent! (Some of us insist we are - or were - 'service recipients' or 'service resisters' (O'Hagan, 1991)).

We may indeed be people who have been diagnosed - labelled - as 'ill' or 'sick'. We have usually been 'treated' with powerful drugs (told sometimes that we will need these drug interventions - these 'medications' - for life) and other 'therapies' (like electro-convulsive therapy - or *'electroshock'* as it is called in the U.S.). We are generally included in disability legislation as 'mentally ill' people (e.g. *'Caring for People'* White Paper), or as 'mentally disordered'. We are included, for example, in the Disabled Persons (Services, Consultation and Representation) Act 1986 as people 'suffering from a mental disorder...' (along with people who are; 'blind, deaf or dumb, and other persons who are substantially and permanently handicapped by illness, injury or congenital deformity' (MIND/RADAR, 1986). The language of the National Assistance Act 1948 is retained!). Elsewhere, we have become people 'with long-term psychiatric disabilities'. We may receive Invalidity Benefit and Disabled Living Allowance, be referred to Disablement Resettlement Officers when looking for work, and so on. That we have become 'disabled' through such legislation does not, however, settle the matter of definition, either for system survivors or for disabled people. (It does settle, however, the debate for the Establishment - we are people with 'disorders').

System survivors are included under the Southampton C.I.L. definition because we, apparently, have 'hidden impairments'. I view this development with dismay. Far from furthering our struggles as 'system survivors', this definition reads to me as firmly placing us back into *medical* models of 'mental illness', 'chemical imbalances' and so on. Some of us have long been intent on challenging such concepts! (Plumb A.E. 1993). This is a sad irony for a disability movement which has done so much to shift the emphasis away from a medical to a social approach to physical impairment.

One of the disabled people to effectively advocate a shift away from a medical to a social approach to disability was Vic Finkelstein. In an article in the 1975 New Year edition of *'The Magic Carpet'* (the journal of the Disabled Drivers Association), he focussed on a recent survey by Amelia Harris and colleagues for the Office of the Population, Census and Surveys (O.P.C.S.). In this survey, describing 'different aspects of the disabled', three definitions were made. These were:

> *impairment* 'lacking part or all of a limb, or having a defective limb, organ or mechanism of the body';
>
> *disablement* 'the loss or reduction of functional ability'
>
> *handicap* 'the disadvantage or restriction caused by disability'.

Vic Finkelstein suggested two changes to these definitions:

> Firstly, that the cause of handicap lies within the society which disadvantages impaired people by taking no, or very little, account of their physical condition and consequently does not provide the solutions - for example, providing ramps ...the handicap is caused by having steps into buildings and not by the inability to walk...

> Secondly, I suggest changing the definitions of the words handicap and disability around. In this way a person is disabled when he or she is socially prevented from full participation by the way society is organised (in the broadest sense).

> (Finkelstein, 1975)

Finkelstein's preference for the term 'disability', rather than 'handicap', lies interestingly in a wider *social* definition of disability. He refers to its use in the 1950 Constitution of India. It is used here with reference to the caste of Untouchability. This wider social use of 'disability' seems to me now to be part of the confusion as to who is, or isn't, 'disabled'. Finkelstein, however, is quite specific as to whose situation he is exploring - the situation of people who are *physically impaired.*

This is further explored and defined in *Disability Challenge No. 1* published by the Union of Physically Impaired Against Segregation (U.P.I.A.S. 1981). The editorial states:

In our collective struggle to understand the truth underlying our impoverished social situation we were led - through the pooling of experience and through discussion arising from it - to recognise two clear features. First, we are members of a distinct group with our own particular physical characteristic (physical impairment); and second, that society singles this out for a special form of discrimination (disability).

The Union's definitions were:

> *impairment* lacking part or all of a limb, or having a defective limb, organ or mechanism of the body; and

> *disability* the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people with physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is, therefore, a particular form of social oppression'.

> (UPIAS/Disability Alliance, 1981)

Handicap has disappeared from the discussion.

In the definition with which I began this article, special emphasis is placed on *hidden* impairments. Included amongst people with *hidden impairments* are, it seems, system survivors. There is a crucial question here - what is meant here by 'impairment'? In keeping with the definition of impairment above, does this mean a 'defective ... mechanism of the body'?

Defining Our Experience

Survivors, like disabled people, have also sought to define our experiences and situation. What brings some of us together, as in SSO, is our experience of the psychiatric system or 'mental health services'. This forms the basis of our definition, as in the SSO Constitution, namely

> a "survivor" is someone who receives or has received mental health services,

rather than a definition of some common personal characteristic or characteristics. An international network of Mental Health System Survivors (MHSS) also used this definition when they prepared and presented a Policy Statement. This, they wrote, is:

a working definition of the oppression of 'mental patients' and ex- 'mental patients' including inmates, ex-inmates, and other survivors of the 'mental health' system... a tentative strategy for our liberation...

(MHSS 19B6, 1992)

The MHSS in this perhaps little-known, but very significant statement, go further to define whom system survivors are or are not. They say:

'Mental health' system survivors are people who are neither 'crazy' nor 'mentally ill' nor genetically distinguishable from anyone else. We are now, and always have been, fully human. We are not a different type of people from the rest of society. There never has nor will be anything 'wrong' with us. Rather, we have been victimised by the 'mental health' system because of our hurts and the hurts of those around us. Because of our trying to get help in the only ways or places we know of, because we belong to certain oppressed groups, or refuse to fulfil some of society's prescribed roles, or protest the wrongs of society, we became involved in the 'mental health' system because of our own or others' hope that we would be made more 'co-operative'. Our bodies and lives have mostly been damaged and constrained by interacting with the system. We have been, or are being institutionalised or otherwise 'treated' by 'mental health' professionals. We have been hurt by watching this happen to someone close to us.

What this is saying quite clearly is not that we don't experience difficulties or need support, but that our difficulties lie in hurt, oppression, a refusal to fulfil prescribed roles ...and society's response to these. This reflects a more widespread shift away from talk of 'illness', 'disorder' or 'defective mechanisms' (chemical imbalances) to talk of *distress* or *dissent.* An example of this shift is 'A Charter of Rights' drawn up by Hackney Mental Health Action Group (H.M.H.A.G.) for people in mental distress, (see also *Lambeth Link* 1990). The philosophy behind the H.M.H.A.G. Charter is that:

All people have been emotionally hurt but the severity and nature of their distress and the circumstances of their lives cause some people to seek help or to be forced to accept treatment from the mental health services. We refer to people in either of these situations as mentally distressed.

Distress and *dissent* place us as firmly in a relationship to our society and culture as does the U.P.I. A.S. definition of *disability* for physically impaired people; except that we are not bound by any agreed definition of *impairment,* hidden or otherwise (although there are many people who have iatrogenic - medically induced - impairments through psychiatric treatments (Breggin, 1979, 1991; Frank L, 1990; Morgan R.F.M., 1991)).

In talking with other survivors who are undecided as to whether or not they are 'disabled', it seems to me that it isn't *impairment* that people feel they have in common so much as *disablement* in the way that Amelia Harris used the term (i.e. a personal 'loss or reduction of functional ability'). Vic Finkelstein deliberately worked his definition not to deny this reduction of 'functional ability', but to shift the focus from this personal definition to a social definition of disability (to the absence of ramps rather than the inability to walk). Either way, there remains the crucial issue as to whether this *reduction of functional ability* arises through human experiences of *distress* and *dissent.* The MHSS use the term 'mental health' reluctantly. They say:

We use the phrase 'mental health' in order to identify the system as it is commonly known; however, we cannot understand ourselves within the framework of health and disease. It has never been rational to label us 'sick' or to separate us from those thought to be 'well'...

Overwhelming fear, deep emotional pain, unremitting despair, withdrawal, the voices and visions I have experienced, have at times left me seemingly 'incapable'. It is my view, too, however, that these have to do with distress and dissent - to my life's experiences within the culture and the social

structures of our society - and scarcely anything to do with chemical imbalance or aberrant genes. (Plumb A.E. 1993) Chemical interventions may be experienced by some people as helpful, but this does NOT PROVE any defect, only the mood-changing ability of the drug. As Viv Lindow has written:

> Mental 'illnesses' have biochemical correlates (as does laughter and all other emotional expression) but no physical causes have been demonstrated, despite decades of expensive research here and in North America.
>
> (Lindow, 1991)

Powerful psychiatric drugs and 'treatments' can be administered without consent, quite legally, because of the belief that 'mental illnesses' exist. Kate Millett, author of *'Sexual Politics'* and *'The Loony Bin Trip'* writes in *NAPS News* (National Association of Psychiatric Survivors), 1992, that we are:

> ...survivors of one of the meanest systems of oppression ever developed. We are the ones to tell the truth, to bring the word that mental illness is an illusion, intellectually and scientifically, but also a system of social control of unprecedented thoroughness and pervasiveness. It is our role to expose this illusion, while freeing us all, for we are all constrained, oppressed, limited, intimidated by this phantom of mental illness.

In my personal experience, drugs administered without my consent were a violation of my body and self.

It is beyond the scope of this paper to go further into justifying these statements, except to emphasise that in our searches for evidence of illness, we have not found anything the slightest bit conclusive. Far from it, what we find is highly subjective and unsubstantiated definitions based on apparent 'symptoms' of mental illness, the labelling of certain behaviours as symptomatic of illness. (Early symptoms of 'schizophrenia' included smoking cigars in church! (Hill, 1983)). We find research that has popular appeal but doesn't stand up to closer scrutiny - as in the case of the search for a gene for 'Manic depression' in the Hamish community ([5]). What is important here is that these statements, by survivors, have been made.

Just what the place of 'definition' is in the context of overall struggle is another big question! Definitions can too easily become the material of remote academic debate, or the entrenched dogma of a few. Nevertheless, in order to challenge the ways in which we are commonly perceived and treated in our society we have to define ourselves or our own situations. The definitions I am exploring here from the UPIAS and the MHSS are not uncontroversial, nor everyone's preference. There was, for example, a long and sometimes acrimonious debate between those who defined themselves as 'disabled people' and those who believed that this gave a negative image and spoke of themselves as 'people with disabilities' (or later, as 'physically challenged', or 'differently abled' (UPIAS, 1981)). 'Mental health service user' is a term often used unquestioningly yet is strongly opposed by people like myself who insist we are, or were, 'service recipients' or even 'service resisters' (O'Hagan, 1991).

The definitions of the UPIAS and MHSS are, however, distinctly collective definitions, carefully worded after much discussion, and published within the context of active struggle against oppression. They are therefore especially relevant to the discussion as to whether 'system survivors' are, or are not, 'disabled' and therefore a part of the disability movement.

Our Own History

The definition supported by the Southampton CDL seems to be designed to ensure that no-one who could fell into the category of 'disabled' is excluded. But there is also, sometimes, a desire of some disabled people to take people like myself 'under their wing'. A reader of *'Coalition',* for example, wrote in a letter in December 1990 that he suspects:

...that there are thousands of people who are handicapped by the fact that their disability is not obvious ... Manic depressives and paranoid schizophrenics are ... (an) example of what I mean

He further suspects disabled people:

...could identify and care about people who have had a nervous breakdown caused by something within our society.

A social connection is being made here, but what concerns me here is lack of knowledge of OUR history of struggle, and the prospect of disabled people speaking on our behalf without this knowledge.

The earliest recorded protest I have seen referred to is *The Petition of the Poor Distracted People In the House of Bedlam* in 1620 (Read J. and Wallcraft J., 1992). More well documented, however, are protests in the late nineteenth century. There is documented evidence of an Alleged Lunatics' Friends Society (ALFS) that was active from 1845 to 1863, and of a later Lunacy Law Reform Association 1873-1885 (led by Louisa Lowe, a vicar's wife who had been incarcerated by her husband because of her spiritualism (Hervey N., 1986)).

ALFS began not unlike UPIAS (initiated by a letter from founding member Paul Hunt to *The Guardian,)* with a letter to *The Times* (April 1846) by Richard Paternoster inviting other people who had been confined to join him in a campaign to redress abuses in the 'madhouse system'. The general philosophy, according to the historian Nicholas Hervey, stemmed from:

...traditional appeals to Anglo-Saxon law, Magna Carta, the writings of Edward Coke, and, more controversially, Paine-ite concerns with the rights of individuals to certain inalienable freedoms within the welfare of society as a whole. Each patient should have a voice in his own confinement and care, and access to legal representation.

Members also identified forms of 'moral treatment' as repression. One member, John Perceval (who had been placed by his brother in a 'purpose-built' madhouse considered to be one of the foremost institutions of its kind!) criticised the asylums. He claimed that patients were first crushed, 'and then discharged to live a milksop existence in society'.

The early objectives of ALFS were:

...to campaign for changes in the lunacy laws, which would reduce the likelihood of illegal incarceration and improve the conditions of asylums; to offer help to discharged patients, and to convert the public to an enlarged view of Christian duties and sympathies ... (and) to forward any matters the (Lunacy) Commission might overlook.

Hervey explores these developments in depth, though not without his own views as to 'strategical errors'. It is Hervey's view, for example, that:

...by making the unfortunate antecedents of several of its members a matter for pride, rather than distaste, the Society reduced its credibility as a rational force. In addition, its fearless exposure of upper-class sensibilities regarding the privacy of this subject intimidated the very groups that normally patronised charitable organisations. It also became a matter of principle that the stigma attached to ex-asylum inmates should never be a barrier to normal integration.

This represented to Hervey a 'hard-line' approach of which Hervey is not wholly supportive!

Unfortunately, this organisation folded, and it seems to me that we have had to start again, more than a century later, still pursuing the same issues! What appears to have happened in ensuing years is the development of a different kind of organisation, the National Council for Lunacy Reform (founded 1920) following two private (and probably 'professional') conferences on lunacy reform - an organisation akin to National MIND in its organisation and interests?

The 1970s however, saw renewed 'grassroots' activity - as much as there was in the Disabled People's Movement during that decade. In December 1972 a pamphlet, *'The Need for a Mental Patients' Union',* was produced by an ad hoc group of mental patients and ex-patients. It took the view that *'psychiatry is one of the most subtle methods of repression in advanced capitalist society'.* (Durkin, L. and Douieb, B., 1975).

In 1973, a national conference was held at Paddington Day Hospital. Over 150 people attended, of whom over 100 were patients and ex-patients. A steering group was set up and the M.P.U. was formed. A Declaration of Intent was also produced. It is not appropriate here to describe later events - a fire in the MPU's squat and office in which a founding member died, the emergence of COPE (Community Organisation for Psychiatric Emergencies) and PROMPT (Promotion of the Rights of Mental Patients in Therapy), and ultimately CAPO (the Campaign Against Psychiatric Oppression) in place of the MPU (see Van de Graaf, 1986; there is also a very powerful poem by Mike Lawson describing this development (Lawson M. 1988)); nor to describe the complementary movements in North America - the Mental Patients Liberation Fronts, the Mental Patients Association, the Madness Network News... and in Europe - the Clients Unions in Holland, the Socialist Patients Collective in Heidelberg (see Chamberlain J., 1977, 1987; Spandler H., 1992, Van de Graaf 1986/89; Van Hoorn E., 1988; Weigant H., 1985). The point is that there was a lot of struggle and activity during this period!

It is, however, relevant to draw attention to the activities of the Manchester Mental Patients' Union, as this followed a somewhat different path to the 'London' MPU, and is less widely known. This group had a contact at Prestwich Hospital (and a phone number in Manchester's Grassroots bookshop). They produced a booklet, *'Your Rights in Mental Hospital',* (with support from Manchester Community Action, Manchester Big Flame and Grassroots Bookshop). And they were negotiating for housing under tenant control with a housing association (at the same time as the Rochdale Housing & Disability Group were likewise negotiating with a housing association to develop a 'Grove Road' scheme locally ([6])). They had links with inmates at Moss Side Top Security Hospital (now 'Ashworth') and individual members were active in the South Manchester Law Centre. Struggle and resistance, unfortunately, took its toll, I was told, and by the early eighties the Manchester MPU folded.

The 1980s (in particular the late 1980s) and the early 1990s saw people who were receiving, or had received 'mental health services' (and allies with whom 'survivors have had closer links with than disabled people (7)) speaking out, and taking action, individually and collectively. Local support and action groups and forums formed and produced, amongst other things, documentaries like *We're Not Mad, 'We're Angry'* (ITV Television, C4 ,1986; Albany Videos, 1986) and *'From Anger to Action'* (Mental Health Media Council, 1992), Charters (Lambeth Link, 1990; HMHAG), Codes of Practice (Camden Consortium, 1988), responses to government documents (Beecroft M., Conlan E., Field V, Hoser B. and Sayce L., eds. 1990), guidelines for 'empowering users of mental health services' (Read J. and Wallcraft 1,1992), poetry (CAPO, 1990; Survivors Poetry, 1992) .... (a list of activities which reflects the closer links with allies and with service provision, but which were the work of 'survivors').

During this period Survivors Speak Out was set up, in 1987, as a national network of 'survivors'; along with MINDLINK, a 'consumer' network within National MIND in 1988; a Scottish Users Network; a Voices Forum (of National Schizophrenia Fellowship members); and N.A.N., now U.K.A.N. (a U.K. Advocacy Network). The late 80s, early 90s, saw participation in a European Network of Users/Ex-users and Client Unions, and in a World Congress of Psychiatric Survivors. (The WCPS was set up in some ways like the Disabled Persons International (D.P.I was a response to the absence of people with direct experience in Rehabilitation International; WCPS was a similar response to the World Federation of Mental Health). This participation reflects international links over the years with Holland, Italy, Czechoslovakia, Iceland, North America, New Zealand, Japan (recorded in back issues of *'Asylum'),* Some of these links came from allies working for alternatives to psychiatry - but most links, as I see it, were and are a part of a growing international 'survivor' movement.

Common Goals?

Given that we have as long a history and as broad a struggle as disabled people, what should our relationship be with the disability movement? In the International Year of Disabled People (I.Y.D.P.) 1981, there was a concerted effort by charities like MIND to ensure that 'mentally ill' people were not excluded from a share of the cake, from the resources on offer for facilities and services for disabled people. And resources of various kinds are possibly still a significant attraction? But there are also other issues which draw us together. More recently, there have been campaigns by disabled people for anti-discrimination and for civil rights legislation, similar to that achieved by disabled people in the United States, for 'rights not charity', which some survivors have identified with. There has been pressure for S.S.O. to join the B.C.O.D.P. (British Council of Organisations of Disabled People) - both from members of the B.C.O.D.P. and from some of our own members. The apparent success and public profile of the disability movement is also an attraction.

In the USA, the 'psychiatric survivor' movement appears to have submerged itself wholly within the disability movement. A representative, Judi Chamberlain, said at the White House on the passage of the Americans with Disabilities Act:

> One of the reasons we were able to pass the Act was the development of a coalition of groups representing all disabilities, including my disability, people with psychiatric labels.

Psychiatric labels - a disability? The U.P.I.A.S. considered its relationship with 'other oppressed groups' in its Policy Statement. They wrote:

> The particular form which oppression takes in this society differs somewhat for each distinct oppressed group. Some, such as people who are called 'mentally handicapped' or those labelled 'mentally ill', clearly have a great deal in common with us. *Full membership of our Union is, however, based simply on the fact of physical impairment*. This is because we believe the important thing at the moment is to clarify the facts of our situation and the problems associated with physical impairment. But it is fundamental to our approach that we seek to *work with other oppressed groups and support their struggle to achieve a decent* life. What all oppressed people share is a vital interest in changing society to overcome oppression, and the Union is therefore anxious to join in common action to achieve such change' (my *emphasis*)

– joint action without loss of political identity.

I was an *Associate* Member of the U.P.I. A.S., accompanying my partner, who is disabled and was a *Full* Member of the U.P.I.A.S. to meetings. At that time, I perceived myself as 'emotionally injured' by society (never 'mentally ill'), and pondered the similarities between our various situations! But it has been the words 'system survivor' that I came to identify with most.

Mike Lawson, a survivor whose involvement with our struggle goes back to the early days of the M.P.U. has written:

> When your headlights hit a hedgehog and it curls into a ball as a survival instinct, you don't call that catatonic schizophrenia. Yet when a person feels so helpless and distressed that he curls up inside his own reality because the other one is too painful to contemplate, doctors call that paranoid schizophrenia and say it requires lifelong treatment with drugs.

> (Lawson M., 1987)

I now see myself and others in a broad sense as:

- survivors of the psychiatric system

- survivors of our social structures and institutions

- survivors of cultural practices and values.

(Plumb, A., 1993)

Taking Mike's analogy further, one may switch off the headlights and let the hedgehog go on her way! Alternatively, we may put all efforts into changing the response of the hedgehog - persuading her to ignore the headlights from which she is protecting herself; or administering drugs to the hedgehog so that she is no longer responsive to bright lights (turning her response to lights to personal pathology rather than environmental response).

The U.P.I.A.S limited Full Membership to the fact of physical impairment so as to focus on the problems - and solutions - in the relationship between contemporary social organisation and impairment. The advert with which this article begins came from a Centre for Independent Living. If we shift the focus from defining 'disabled people' to looking at 'independent living' then, indeed, 'system survivors' are among people who may need support in attaining 'independent or integrated living'. But, as the saying goes, 'what may be gained in breadth is lost in focus'.

Perhaps the more general social use of disability (which appealed to Vic Finkelstein) now confuses the issue? It seems to me that requiring support - or being restricted - *in any way* - has become synonymous with 'being disabled'. But, if disability is understood in this way, shouldn't the C.I.L. include, for example, pregnant women? The Home Help service was, after all, originally set up to support women coming out of hospital following the birth of babies, And what about children? Children are prevented from independently using both domestic and 'public conveniences' because they cannot reach the hand basins, let alone the taps or driers! So too is their mobility restricted - not least through the amount of traffic on roads they need to cross.

The question arises as to whether what we have in common is enough to justify us submerging ourselves in the disability movement? How important are our differences? As mentioned earlier, the U.P.I.A.S. definition of 'disability' was:

> the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people with physical impairments and thus excludes them from participation in *the mainstream of social activities*. Physical disability is therefore a particular form of social oppression.

> (UPIAS/Disability Alliance, 1975) (my *emphasis*).

The emphasis here is on the exclusion or restriction from mainstream activities. If, however, the focus is on 'distress' and 'dissent'; if, as the MHSS policy statement says, we may become involved in the psychiatric system because we

> refuse to fulfil some of society's prescribed roles, or protest the wrongs of society

then entry into, or back into, *mainstream* activities may not be our goal! At the very least, it requires qualification. If what we are experiencing is oppression caused by the way in which contemporary social organisation gives rise to and responds to distress and dissent, then our demands are for a *changed* society, and room for people who do not wish to join 'the mainstream'!

From the perspective of system survivor we may explore our relationship with contemporary society much further. As survivors we may speak out variously:

- against abuses, violations and inadequacies of the psychiatric system today (while not forgetting atrocities of the past);

- against our oppression in society as children, women workers, young people (against experiences that have put us down or driven us on);

- against repression in our culture (experiences that have forced us to be other than ourselves under the guise of parental obedience, good behaviour, religious duty, 'normality and so on'. (Plumb A., 1993)

And we may take action, most notably, *for social change.* A vast agenda! And there are two other crucially important terms. These came out of the mental patients' liberation groups in N. America. These are Mentalism and Sane Chauvinism. Mentalism I understand as the oppressive way in which human distress is perceived and responded to within our culture. Whilst 'Sane Chauvinism' is exposed in the popular use of words like 'crazy', 'mad', 'lunatic', 'loony', 'schizophrenic', 'manic', ...words invariably used to discredit, though some of these words have been reclaimed at times by survivors.

The problems - and solutions - we may feel are crucial in relationship to distress may not be the same as those related to disability. Only recently Colin Hambrook has written in *'DA1L' (Disability Arts in London),* Issue 88, March 1994:

> Privileged as I felt to have my work accepted for recent exhibition organised by LDAF (London Disability Arts Forum), entitled 'How We Like It', I realised the context of my work was inappropriate. This feeling is weighed in balance of the gulf that exists between issues that surround the disability movement, as opposed to issues which underlie the focus for the mental health system survivors' movement.... '*How We Don't like It*' would be a more appropriate title to accompany my work.

Colin Hambrook perceived what was, for him in this exhibition, a crucial difference; that

> whilst it is completely appropriate for 'disabled' artists to make artistic statements which support the fact of their strength as human beings in a disabling world, the survivors movement pivots on the need to share and be accepted for feelings which are denigrated as unacceptable weaknesses by an uncaring society which places no value on the ability to withstand and surmount impossible and oppressive situations.

Pressure to join the BCODP (with its group membership) poses a problem for SSO, To join would be to *impose* a definition of 'disabled' on ALL members of the network - in my view quite against the ethos of SSO. The problem for GMCDP, with its individual membership, is less straightforward. For there is an inescapable irony - those joining under the GMCDP definitions of disability would be admitting to an impairment, thus legitimising and maintaining the link with 'illness'. Yet, historically, challenging this link has been central to patient/ex-patient movements (and this challenge remains crucially important, not least with the race to locate apparently aberrant genes). The disability movement has a greater public profile because, through its struggles, access issues (if not the broader equal opportunities and equality) are becoming publicly accepted, 'common sense'. It is taking longer for survivors' demands to be publicly accepted. Nevertheless, I believe that we are breaking through, that there is a public receptiveness to what we are saying about distress (if not dissent). It seems to me quite the wrong time to lose this impetus by submerging ourselves within the disability movement.

In common with disabled people we protest at being discriminated against, segregated and excluded. Indeed, like disabled people, we have faced extermination in the past (Breggin R.P., 1976) and possible elimination through genetic screening and interventions in the future if present-day eugenicists have their way. Like disabled people, we have experience of the Health, Social Service and other 'authorities'. Like disabled people, we too are objects of pity and charity. Like disabled people we require support that is appropriate to our needs as we see them. In common with disabled people, we have a 'movement', with a history and our own definitions. But we do not all agree that we have a physical impairment, hidden or otherwise (only that attributed to us by psychiatry). And the practicalities of change we are struggling for are in many ways very different.

part two

Symposium Papers – Day One

Setting the scene

Helen Spandler

I want to start by thanking Bob (Sapey) and the Centre of Disability Research at Lancaster University for hosting this event, and also to Jill (Anderson) at Mental Health in Higher Education. It has been a pleasure organising this event with you both.

I want to kick off by offering some initial comments which I hope will help facilitate discussion during the symposium.   As you all know, the focus of this event is the relevance of the social model of disability to mental health. This focus matters in a number of important ways. Most obviously, the social model of disability originated within a very important social movement, the disability movement – this is obvious but it needs re-stating at the outset. Whilst academics have a role to play in this - it's why we are here! – this is not (just) an academic debate. I think we need to keep in mind Mike Oliver's (2011) comments that there has been 'too much time taken up with heated academic and personal debates about the usefulness, inadequacies and relevance of the social model of disability and not enough in applying it to the real life circumstances of disabled people'. I would like us to bear this in mind throughout the day – especially in the final session ('using the ideas') where we explore the implications of these debates for teaching, practice and activism.

It also matters in relation to developing appropriate support and service provision. We might want to think about what theories or concepts help to forge alliances to demand support, defend services and welfare benefits, especially in our current climate of public service cuts. This task is likely to get more urgent in the coming months and years ahead.   In addition (and arguably) the social model of disability is often seen to underpin many current policy developments in mental health – such as recovery, personalisation and social inclusion. We might debate what form of social model of disability this takes (and we might suggest that it is a 'weak' or liberal individual rights version). We might also debate (and criticise) what form these developments are taking, and/or whether they are 'really' informed by the social model of disability. Nonetheless, the social model of disability is often drawn upon as a *justification* for these developments. Therefore, our understanding of what *we* mean by the social model of disability, and how it does (or doesn't) apply in mental health, is important to help us make sense of these developments. For this reason, we have included a special themed discussion about the relationship between the ever thorny concept of 'recovery' and the social model of disability.

Yet, and despite Mike Oliver's important warning, there are serious issues with the application of the social model of disability to mental health which means that we can't just go ahead and 'use it' or 'apply it' in any easy way. Otherwise we wouldn't be here today. Having said that, alliances between mental health activists and disability activists are happening anyway – especially in relation to defending services and welfare benefits - whether or not we have theoretically 'solved' this dilemma or not.

I also agree with Oliver that we need to start with work that's been done by activists themselves. With this in mind, the issues at stake here are best summarised by Anne Plumb's *Distress or Disability?* a discussion document written for the Greater Manchester Coalition of Disabled People (GMCDP) back in 1994. This is why we have named the symposium after this document; it is why we asked you all to reflect on it in your presentations and papers; and why we have invited Anne as a special guest to comment and update it.

I just want to give a brief example of the manifestation of the problem of 'application'.   I have spent a number of years working in a School of Social Work marking undergraduate social work student's essays. One assignment asks students to apply a 'service user perspective' to a case study of family situation involving a woman with a diagnosis of manic depression. Many of the students choose the social model of disability as an example of a service user perspective and attempt to apply this to the case study. Students to tend primarily focus on experiences of stigma and discrimination seen as

resulting from a *pre-existing* 'mental illness'. This application can be important and useful and, for some students at least, leads them to suggest options like direct payments and other mechanisms that might challenge social exclusion. However, in my opinion their resulting analysis is often limited and rarely appreciates the deeper social aspects of mental distress. For example, students paid little attention to past abuse and neglect, including from within the mental health system itself – the very aspects of 'psychiatric survival' that Anne refers to in *Distress or Disability?* In other words, students did not problematise the bio-medical framing of 'mental illness', nor did they question the privileging of medication as the primary (or even the only) intervention.

For example, despite the woman in the case study clearly disliking her current treatment, very few students actually recommended a review of her medication and/or considered any therapeutic alternatives and/or other socialised support. In fact most of them felt that the most important task for social workers was to educate her and her family about her illness, and to make sure she knows why she needs to comply with her medication regime. Set with a wider context, the mental health service user/survivor movement has been extremely vocal in its critique of the over-reliance of medication in psychiatry and the lack of alternatives and crisis provision. Therefore, despite advocating a so-called 'social model' in effect, it could be argued that these burgeoning social workers were potentially letting a 'medical model' in through the back door. As these were common issues across the student cohort, there are important lessons to draw out about the way the social model of disability is applied (and taught) in practice in the context of mental health.

Putting aside the question of the quality of the teaching or the students, one of the key issues is the conceptualisation of the 'impairment' itself. It seems as though the social critique of the social construction of 'impairment' needs to go deeper in mental health. This is partly because disablement in mental health isn't necessarily predicated upon a pre-existing impairment which is then oppressed or marginalised by society or social agents – *but rather constitutes the very thing that is deemed the illness itself*. To put it another way, it is difficult to disentangle the 'impairment' from the social conditions that give rise to it.

Whilst we might, for example, say that there is an identifiable 'condition' which exists in disability – notwithstanding the crucial importance of the social value placed upon it – but that condition is harder to identify in mental health. We could endlessly argue about what the impairment *is* in mental health – and indeed how it might be similar or different from physical illness, chronic illness and disability (and perhaps we should). But for now, I think Anne is right that 'distress' is probably still the best term to use. Yet, however we understand this (whether as mental illness, madness; mental health problems or whatever) it is certainly experienced as distressing for the self and/or others. This means that distress is thoroughly social and deeply relational. In other words, it originates, is manifested and played out in relation to others in a social context.

Perhaps the most important example of this is the social origins of distress. There are now well-established links between particular distressing experiences (especially persecutory voices, self harm and paranoia) with abuse, trauma, discrimination and oppression (See Richard Bentall and colleagues' recent work). This is one of the reasons we have included a themed discussion on abuse, trauma and the social model of disability – and participants are specifically responding to the question of whether the social model of disability and the idea of psycho-emotional disablement can help us understand the interplay between abuse and mental ill health.

So, in a nutshell, if we question the very existence of a discrete mental illness such as schizophrenia and frame it instead as, for example, a reaction to trauma, a spiritual crisis or whatever (as many people are doing), this poses questions for a social model of disability that is based on a priori existence of an impairment. Of course, all disablement is dependent on social context and society – that is the 'strong' case of the social model of disability – i.e. it is the social organisation of society which makes impairment matter. However, I would argue that our mental health is *inextricably* and *irreducibly* interwoven by, and through, our social context.

So, does this mean that the social model of disability is inadequate? Not necessarily. It is perhaps not a matter of the merits or otherwise of the social model of disability as some kind of static model – it is more about *how* it is thought about, applied and used in practice. It is important to see the social model of disability as an evolving, dynamic and strategically employed concept (or tool of analysis). When we consider its application we must include the important revisions and additions made, for example, by Carol Thomas in her feminist materialist 'psycho-emotional disablement' (this will helpfully be applied by Donna Reeve for us here). We are delighted to have both Carol and Donna with us during this symposium.

I think part of the problem is that in mental health we tend to talk about a social model 'versus' or 'in addition to' a medical model (depending on how one positions oneself in relation to criticising a bio-medical model of mental illness). However, this 'social model' ironically isn't actually very 'social'. There might also be this tendency in disability, I'm not sure. I think this might be because we have an impoverished view of both the 'social' and the 'medical'. The 'social' isn't something which just sits outside, 'out there' in society waiting to oppress us. To paraphrase Marx, we are social beings through and through. Therefore, a social model of madness and distress has to fully appreciate the fuller aspects of the social – including social context, social position, social causation and social construction.

In *Psychopolitics,* first published in 1982, Peter Sedgwick had some insights which might help us here. First, Sedgwick understood the importance of the social organisation of society and the social position of people who are deemed mentally ill. He skilfully cuts through the nature/ nurture debate and the dualism of the social/medical:

> 'Never again should it be possible for a lecturer to instruct students, or the public, that 'mental illnesses may be caused by heredity, the environment or a combination of both'…For such dicta, however seemingly authoritative and 'scientifically grounded' simply obscure a number of central features of mental illness and its associated agencies of treatment and care…The accidents of heredity and the blows of the environment do not add up or multiply into the social position and personal identity of being 'mentally ill'...

> (Sedgwick 1987: 25)

Sedgwick's aim was the politicisation of medical goals through a *radically socialised medicine* that is applicable to physical and mental health. In this way, he argued it is perfectly possible for medical doctors to see physical illness as socially caused (e.g. by damp housing, insecticide poisoning, work stress etc). In addition, it is also perfectly possible - and often desirable - for doctors not to prescribe medicines for physical ailments but to advise (for example) rest and recuperation, change of environment, support etc:

> 'to abstain from medicine is potentially as valid a choice for a doctor as to administer a medicine…the model of a condition that will terminate itself if left to run its natural limits, and will only be worsened if their physician meddles with it, is an ancient, but reputable concept in medicine, even if the tendency in our modern technologically based therapies is to stress intervention almost as the rule of the healer's art'

> (Sedgwick 1987:118)

Therefore, medicine itself is not outside the social, it is deeply embedded within the social world - as we know from the influence of 'Big Pharma'. We know that many users and survivors of psychiatry have argued that during a mental health crisis they would prefer minimal (or even no) pharmaceutical intervention but maximum psycho-social support to go through their crisis and even learn from it (Spandler and Calton 2009). In this way medicine should be placed at the disposal of our negotiated social needs. A good example of this is Joanna Moncrieff's 'drug centred model' of psychiatry (Moncrieff 2007). Rather than seeing psychiatric drugs as curing diseases (what she refer to as a 'disease centred model'), she argues that we need to see them as having specific identifiable

mind-altering properties, with effects that may (or may not) be helpful to a person in a particular social context. Thus we need to ask 'what effects might be helpful to a person' rather than 'what drugs do we need to treat this disease?' This also opens up the possibility of seeing other kinds of drugs (e.g. so-called recreational or non-prescribed drugs) as being potentially helpful or harmful in depending on the social context within which they are used.

For me, this *does not* mean a simple recipe of 'social' *plus* 'medical' (in whatever quantities). This seems to be the rationale of multi-disciplinary teams of mental health professionals, each attending to demarcated 'medical', 'social' or 'occupational' needs. Nor does it necessarily mean a 'social' *versus* 'medical' approach.   It *does,* however, mean an understanding of distress which is deeply and consistently social and relational.

Finally, one of the things Sedgwick under-estimated was the intellectual and political contribution of mental patients or survivors themselves - what might be called, following Gramsci, 'organic' or 'movement' intellectuals.   Like Sedgwick's *Psychopolitics,* Anne Plumb's *Distress or Disability?* remains unsurpassed – either inside or outside academia.   Partly this symposium is about dialogue – between movement activists and academics. It is also about bringing this work *into the academic arena* (it was written as a discussion document for activists). Mimicking Sedgwick I'd like it 'never again' to be acceptable for academics writing about this issue not at least to cite this (and/or other relevant work by survivor activists and theorists). We might not necessarily agree with it - it might be a 'point of departure' as we academics are fond of saying - but it needs to be recognised as the foundational text that is surely is.

So, I hope that together we can surpass *Disability or Distress?* over the next couple of days. I don't expect we will necessarily develop a consensus, but perhaps we can think more deeply, and develop more nuanced theory that is relevant and applicable to the questions posed here. And with this I am delighted to welcome Anne Plumb as our first main speaker...

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Incorporation, or not, of MH survivors into the disability movement

Anne Plumb

'*Distress or Disability*' (Plumb, 1994) was a discussion document for activists. This paper continues to focus on the history and dynamics of grassroots activism, in particular the UK's Union of the Physically Against Segregation (UPIAS) 1973-90 and Survivors Speak Out (SSO) 1987-; On the UPIAS because of its Social Approach to– or Interpretation of – Disability that underlies Oliver's Social Model of Disability (Finkelstein, 2002). And on SSO because it also had a social approach – though this was not presented, nor picked up, as a social model. Should this be jettisoned in favour of a disabilities model?

First a quote from a UPIAS activist, Ken Davis, on definition.

> The political significance of (our) definitions lies in the fact that they are a statement coming out of the direct experience of disability; ... a tool for measuring the role and relevance of existing service systems; ... and they lift the veil which obscures the ugly face of discrimination against disabled people in contemporary British Society

and, with reference to the Derbyshire Coalition of *Integrated* Living (DCIL), as it was then,

> success would depend as much upon the theoretical soundness of ... (our) working as upon political awareness and application of seeing through.

> (Davis, 1990 p3-4)

The UPIAS 'unashamedly' identified itself as an organisation of physically impaired people and defined themselves as members of a distinct group with their own particular characteristics (physical impairment) which society singles out for a 'special' form of discrimination (disability) (UPIAS, 1981 editorial). Since Britain had

> the necessary knowledge and the advanced technology to bring physically impaired people into the mainstream of life

the Union aimed to have all segregated facilities for physically impaired people replaced by arrangements for full participation in society (UPIAS, 1974). Note this refers to Britain. Social models are relevant to the particular societies out of which they arise (Cuba Rehabilitation Study tour 1985, Finkelstein, 2002).

Davis described their viewpoint as 'setting out from the extremity of social deprivation in residential institutions'. Writing about the DCIL, he mentions the Seven Needs, 'seven areas for practical action if the phenomenon of disability is to be overcome' - 7 primary needs plus 3 secondary needs (Davis 1990). The DCIL grew out of the Derbyshire Coalition of Disabled People (DCDP) negotiating a Statement of Intent with the Country Council (documented for the Disability TV series, Link) (Davis and Mullender, 1993). This was local labour socialism, democratic control of public provisions. The same can be said of UPIAS activists in Greater Manchester (Lumb, 2008) and Lambeth (UPIAS, 1981).

Paul Hunt emphasised that the Union did not claim to represent or speak for other disabled people. On the contrary, it recognised conflicting views existed and wished to promote discussion aimed at making clear what these differences are (Hunt, 1975, UPIAS, 1976) .For Finkelstein, The UPIAS was a *vanguard,* trying to raise the level of discussion among disabled people about their place in society (Finkelstein, 75.2. p16). For the record, at least half of those voting on the UPIAS Policy Statement were women (UPIAS Circular). And Paul Hunt's 'Stigma' had 12 personal accounts, 6 of them by women (Hunt, 1966). The UPIAS definitions were never intended as an all encompassing, inclusive description but *tools for analysis* (Finkelstein, 2002). I note Carole Thomas's reformulation of disabilism as

a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being

(Thomas, 2007).

But also Vic writing in 1975:

society through its social relationships (both inter-personal…and physical) disables people who have physical impairments.

(Finkelstein, 1975 ii)

And Paul Hunt's critique of A Life Apart, a pilot study of residential institutions, certainly includes attitudes (Miller and Gwynne, 1972, Hunt, 1973).

With regard to other oppressed groups the UPIAS stated:

Some (groups) such as people who have been called 'mentally handicapped' or those labelled 'mentally ill, clearly have a great deal in common with us.

Full membership of our Union is …based simply on the fact of physical impairment. This is because we believe the important thing at the moment is to clarify the facts of our situation and problems associated with physical impairment. But it is fundamental to other approach that we will work with other oppressed groups….

(UPIAS, 1974).

SSO also adopted a social approach. Lorraine Bell, a founding member, has written:

… we decided on our name: survivors of a mental health system which eroded our confidence and dignity and survivors of difficult life experiences which took us into the system.

(Bell, 1987)

Peter Campbell has written that he is

caught up in a mental health system more complex and deep rooted than services alone. As a result of this type of analysis I believe system survivors are more radical in their demands

(Peter Campbell, 2001).

'Survivor' was probably borrowed from an international organisation of Mental Health System Survivors (Mental Health System Survivors, 1986; Plumb, 1994)

SSO's aim was, above all, self advocacy. In the Challenge of Self Advocacy, I wrote that

labels like 'psychotic'… strip us, not of some, but nearly all credibility Some of us also insist on the validity of our experiences.

(Plumb, 1993)

Focussing on the *discrediting* of our voices and experiences by society is as radical as the emphasis in the social model of disability on *exclusion.* And secondly, our aim was to speak out, a process already begun. Minutes of SSO meetings (1987) show participants from some 16 organisations from Glasgow to Southampton. And Hackney Mental Action Health Group had already produced a Charter of Rights of People in Mental Distress (HMAG, 1986).

SSO was a network which aimed to share views, experience and information about what was being done to create changes; look at the provisions and choices we would like to see available; organise a national conference; and actively support the formation of new groups. (SSO report Jan 1987).Why was such a network necessary? Survivors spoke of the *medicalisation of distress and dissent*. (Plumb,

1993). William Sargant, a founder of the clinical model in the UK, recognised the impact of social circumstances on people (at least initially), but believed it was futile to try and change these. He also opposed psychotherapy (Sargant, 1966 p32). Adopting the term Mental Distress was a *distinctive and radical challenge* to the medical/clinical model.

Mike Lawson used the metaphor of a hedgehog, caught in a car's headlights, curling up as a survival instinct. (Hodgkinson, 1987, Plumb, 1994). Influenced by the UPIAS (as an Associate member accompanying Ken Lumb, a Greater Manchester disabled activist) I first thought of emotional *injury* rather than mental illness but developed this into *distress as a social relation* in a presentation to the Women & Psychology Conference Birmingham 1990 (Plumb, 1987, 1993). This paper was the culmination of my attempts to make sense of, and to cope with, my own experiences, labelled manic depressive psychosis in 1968. Some survivors spoke of Mentalism and Sane Chauvism (Berry, 1985; Chamberlin, 1987; Plumb, 1993)

My experience of the SSO national conference 1987 (Edale), was that many of us had experienced the worst of psychiatry and the mental health system, but the tone was mild compared to Support International Coalition, now MindFreedom, set up in 1988 with roots in US Liberation Fronts some of whom used the term 'survivor of psychiatric assault'. "A Charter of Needs and Demands" was unanimously agreed at this conference. Demands included recognition of first hand experience; representation on statutory bodies; non-medical community services, including crisis intervention; independent monitoring of drugs; legal redress; ending of discrimination… (SSO, 1988). Like the UPIAS, SSO was focusing on *out there.* Like the DCIL, its demands were bottom up.

SSO was not against all medication. At the very least, medication is a fall back position supporting us in the absence of anything else. Rather SSO's concern was

> exposing the concealment and ignoring of the iatrogenic/unwanted effects and it's use as social control. We called for non-medical alternatives and sought other ways of dealing with our situations, (Bell 1987 ii, Mental Health Foundation 2001).Without these, there is no such thing as informed consent to psychiatric interventions.

> (Plumb, 1999)

Of course, not everyone shared this perspective. Rachel Perkins, for example, asserted that:

> In our society, there are clear dividing lines between understandable distress and apparently incomprehensible madness… so let's dispense with distress, and embrace Mad Pride.

> Perkins 1999

And Elizabeth Wurtzel, author of Prozac Nation

> There was … a fierce physicality to my depression –And I knew there was some medicine for these feelings.

> (Wutzel 1999)

But I'm equally assertive that

> I knew I was not ill. …Medication distressed and confused me further.

> (Plumb 1999)

But, as with the UPIAS, SSO did *not claim a representative voice* (Campbell, 1990). SSO co-existed alongside other significant mental health organisations that were emerging. (Mindlink, UKAN, Hearing Voices Network…)

On the relationship to other groups, Peter Campbell suggested that we should perhaps look for *alliances* with disabled people, sharing our opposition to the medical model, and with radical mental health workers. But he added:

One aspect of the problem is that we have lost control through working with groups who are powerful than us, more organised and have more urgent agendas.

(Campbell, 2001)

Meanwhile, Peter Beresford**,** along with Gloria Gifford and Chris Harrison wanted closer involvement of survivors with the disability movement and for SSO to join the BCODP (British Council of Organisations of *Disabled* People) (Beresford 2000)

One of Peter's claims was that

the disabled people's movement had at least made some progress… with the passage of the Disability Discrimination Act 1995

(Beresford, 2000).

But he seems unaware of criticism of the DDA*;* that it was not based on the social model and had been described by a civil liberties lawyer as 'riddled with vague ,slippery and elusive exceptions' (SSO, 1997); that the Rights agenda was seen as having been usurped by voluntary organisations and charities; that the BCODP refused to join the body assigned to overlooking the implementation of the Act and the DRC (Disability Rights Commission) was not hailed as a success by all (Oliver and Barnes, 2004).

By the same token, Peter failed to recognise SSO's achievements. Peter is right that the situation seemed worse with public safety becoming the central concern of government mental health policy (Beresford, 2000). But failure cannot be laid simply at our door. It has also to take into account what we are up against. My view was somewhat different; that

since the Mental Health Act 1983, there had been significant developments in Mental Health Service User and Psychiatric System Survivor perspectives, organisation and action.

(Plumb, 1999).

I have an archive to back this up (Plumb, 2011).

Peter asserted that, regardless of what survivors themselves may think**,** they are frequently officially included as disabled. While this is the case, it's a strange point to make to members of an organisation rooted in self-advocacy. A vote on whether SSO should join the BCODP would have been divisive and further weakened SSO. But it also misses the point that the UPIAS *reformulated* Government definitions (Finkelstein, 1975. 1). Peter also refers to a shared disability, but note the UPIAS definition: A distinct group singled out for a specific form of discrimination (disability). To the UPIAS, this meant focussing on the concrete ways in which society disabled them. Substitute *distresses* for *disables* and we get the concrete ways society *distresses* us. Some overlap certainly, but much more. Liz Sayce went further. Based on her research into the American with Disabilities Act 1990 she dismissed *all* approaches to mental health as discriminatory and proposed instead a Disability Inclusion Model (Sayce, 2000, Plumb, 2002). Peter Campbell, however, added a warning to his call for alliances:

There are dangers in gathering around a flag someone else has planted, just because it flies proudly and has colours similar to our own. But if we have doubts, the answer is not to be colour-less but to raise our own flag with our own true colours and fight on alongside.

(Campbell, 2000)

Why abandon the SSO's approach for a social model of disability when the SSO's approach was as radical and outward looking? And are there dangers in doing so?

Fast forward to 2008 and we have UN Convention on the Rights of Persons with Disabilities (CRPD). In so far as the CRPD defines disability as an interaction between people with impairments and barriers (attitudinal and environmental) hindering full participation this is *a* social model of disability

(CRPD preamble, 1) , though the legalistic approach would not have been supported by the UPIAS (Finkelstein 2008). The Convention includes 'mental impairment', though the World Network of Users and Survivors of Psychiatry (WNUSP), which was closely involved its drawing up, favour psycho-social disabilities, meaning 'societal/cultural limits for behaviour' (WNUSP 2008).

The WNUSP see victory in

> securing recognition of equal legal capacity, liberty on an equal basis, free and informed consent and right to respect for the integrity of persons all without the limitations that had previously been inserted into a document dealing with the rights of users/survivors of psychiatry.

> (CRPD 12, 14, 17; WNUSP, 2008 p 5)

Yet I am concerned. Not with a hard won removal of the usual exclusions relating to 'unsound mind' that are used to justify detention and psychiatric intervention, rather that there is nothing in its place that recognises and understands the often *unexpected mental/emotional/spiritual crises* which may lead to us being perceived as 'of unsound mind'.

The Convention seems consistent with a Madness Model, focused on behaviour and liberal US politics (WNUSP, 2008. Article 3), while 'difficult life situations', part of the SSO definition, are only referred to in the Convention where people, *already with a disability,* experience exploitation, violence and abuse. And psychiatry, SSO's other focus, is nowhere mentioned. Rather the WNUSP see the Convention as potentially *opening doors* for challenging psychiatric interventions, by claiming these to be discriminatory (CRPD 14, 15, 17, 25; WNUSP, 2008 p17.-20, 22). The CRPD is detailed on practical requirements to emancipate people with physical impairments but, once again, only opens doors for the WNUSP to elaborate on our needs (CRPD, 9, 19, 25, WNUSP, 2008). In our keenness to see ourselves as disabled/having disabilities has something fundamental to our struggle as survivors been sacrificed? Mental Distress is not just about our behaviour being limited/barred by our society and culture. Distress arises out of our personal, social, cultural circumstances – and not just in the present, but also from what may have gone before and how we may perceive the future (Plumb, 1993). Without exploration of these, it is difficult to see how we can be supported through difficult life situations. The emphasis in the Convention is on a right to accept or refuse help but this is not a genuine choice unless there are meaningful alternatives to psychiatry.

In 1986, the Hackney Mental Health Action Group (London) drew up a 'Charter of Rights for People in Mental Distress' (added to by Lambeth Link in 1990) premised on a definition of 'mentally distressed' people, where the severity and nature of their distress *and* the circumstances of their lives cause some to ask for help or be forced to accept treatment. It stated that strategies must be developed to deal with the need to intervene in the lives of people actually in crisis, evolved from the experiences of people actually in crisis and of those who have experience of assisting in crisis, and that it is also important to have genuine places of asylum, 'non-medical, humane, safe, caring places' where people can explore their own experiences in a secure environment in their own time (HMHAG 1986). We may have experiences that profoundly challenge the usual frameworks that guide our lives and need new explanations that are not readily available.

And I am concerned at the WNUSP celebration in obtaining a right to equal 'legal capacity' (CRPD Article 12. WNUSP, 2008). Echoes of Szasz here – if we are not mentally ill, then we have agency and full responsibility. If a young woman, in a desperate situation, attempts to take the lives of her child and herself but she survives, should this be judged under the penal system with only accommodations, once in prison, made to any needs related to a disability (CRDP 5, 14)? Does society not bear any responsibility for this person's desperation?

My first crisis highlights the difficulties for me around legal capacity, freedom, and informed consent (CRPD 12, 14). Unmoving and uncommunicative (believing myself to be *accountable to a higher authority* than the State, but unsure of what is required of me) what should be done about me?

Should I be left alone, respecting my will to stay where I am for as long as I like? Or be forcefully taken for a psychiatric assessment, detained in hospital, and given strong neuroleptics, as happened. Or should there be another option – someone available to engage meaningfully with me, some temporary sanctuary provided while the next step is considered (Plumb, 1999 p468). The HMHAG Charter suggests two possibilities: places to go with support away from home and support for people who wish to stay at home in crisis such as practical help, telephone networks, befriending services. Lambeth Link added women only space. Drop-ins, now disappearing under a recovery agenda, led by survivors/service users might be another refuge.

I am concerned that the baby has been thrown out with the bath water with a focus solely on disability (discrimination) and freedoms, important as these are. My final word goes to the HMAHG:

> … a mere charter of rights is of limited value in itself, … to translate needs and aspirations into action requires strong commitment of will and economic resources

> (HMAHG, 1986).

We need to be pioneering meaningful engagement and resourcing alternative support should we, one day, see a landmark legal case, respecting our right to refuse psychiatric interventions. Support that others may also find preferable.

Anne Plumb is a mental health system survivor and activist.

Psycho-emotional disablism in the lives of people experiencing mental distress

Donna Reeve

Introduction

This discussion paper will introduce the concept of psycho-emotional disablism and then work through some of the questions that arose from my reading of '… distress or disability?' (Plumb, 1994). I will show how psycho-emotional disablism has more potential relevance than structural disablism for those experiencing mental distress, because of the emphasis it places on barriers to being rather than restrictions of activity. Psycho-emotional disablism also fits comfortably alongside the existing social model of madness and distress which helps challenge internalised oppression. Finally I consider whether it is possible to completely eliminate the subject of 'impairment' from discussions of the experience of mental distress and end by suggesting some fruitful areas for further thought and discussion.

Psycho-emotional disablism

The term psycho-emotional disablism was originated by Carol Thomas (1999; 2007) as part of her project to unpack the different meanings that disability had come to have in academic and mainstream parlance. Drawing on the UPIAS (1976) statement which informed the social model of disability, instead Thomas proposes an extended social relational definition of disablism:

> Disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the *socially engendered undermining of their psycho-emotional well-being*.

> (Thomas, 2007: 73, my emphasis)

Consequently disablism can be broken down into two strands: structural disablism and psycho-emotional disablism. Structural disablism directly impacts on what people can *do* and refers to the disabling barriers which operate at the public level. For example exclusion from the built environment, discrimination in the work place or information in inaccessible formats, in other words, the disabling barriers typically associated with the social model of disability. On the other hand, psycho-emotional disablism operates at the private level, restricting who people can *be*. For example, having to deal with hurtful comments, stigmatising actions of others and internalised oppression which can undermine someone's psycho-emotional well-being and sense of self.

Whilst the social model does not deny the reality of psycho-emotional disablism, structural disablism has dominated academia, policy and grassroots activism with the consequence that psycho-emotional disablism and its long term consequences are overlooked. Part of this may be linked to the reluctance to engage with psychology because of the prevalence of individual tragedy models of disability and the association of disability with loss; however this has meant that the impact of psycho-emotional disablism on the lives of disabled people has been overlooked. Having to deal with the stares and comments of strangers can exclude someone from the built environment as effectively as a flight of stairs, showing how barriers to being can also result in barriers to doing. In addition, psycho-emotional disablism can be likened to emotional abuse because of its long-term and cumulative effects (Reeve, 2006) and consequently the ways in which someone deals with current psycho-emotional disablism could be expected to be impacted to some degree by prior experiences of abuse.

To date my work has looked at psycho-emotional disablism experienced by people with physical impairments (Reeve, 2008) and those with chronic illness which is often experienced as an invisible/fluctuating impairment (Reeve, 2012). Within disability studies, it has been identified that the survivor movement lacks representation within academic writing and that the disabled people's

movement still has a medicalised view of mental distress (Beresford, 2000). This short paper will present some initial thoughts on whether this different definition of disablism provided by Thomas has anything new/helpful to offer people experiencing mental distress – or does it remain part of the problem in the ways that the social model has been identified (Plumb, 1994).

Psycho-emotional disablism and mental distress

In terms of policy and legislation, people who are given the label of psychosis by the mental health system are identified as disabled people – whether or not they self-identify as such (Beresford, 2000). This brings a measure of protection against discrimination in the workplace although prejudice against this group of people remains firmly wedded to the medical model of madness as dangerous (Beresford, Nettle and Perring, 2010). In line with the findings that people are more prejudiced towards people with mental health conditions than those with physical or sensory impairments (Staniland, 2011), people with mental health conditions experience disproportionate rates of disablist hate crime compared to most other impairment groups (Sin, et al., 2009).

Disablist hate crime is an extreme form of psycho-emotional disablism carried out by a perpetrator whose actions are based at least in part, on their assumptions about the invalidity and less-than-human view of someone they perceive as disabled. It is not difficult to see the negative impact this form of psycho-emotional disablism has on emotional well-being if leaving the house makes one vulnerable to neighbours calling you names based on prejudices about mental health - 'psycho', 'nutter', 'freak', 'schizo' (Mind, 2007: 6). This experience of psycho-emotional disablism on a daily basis could be expected to exacerbate the experience of mental distress – an example of how disablism and 'impairment' can interact with each other.

Whilst I can see how the conventional social model of disability with its focus on removing *structural barriers* appears to have little to offer people experiencing mental distress, the notion of psycho-emotional disablism is far more pertinent to the daily harassments and prejudice that people with (perceived) mental distress experience regularly. By labelling this as a form of disablism, rather than 'just prejudice' (in the same way that yelling abuse based on skin colour would be called racism and not prejudice) then it is clear that the solution to these disabling psycho-emotional barriers lies in changing society and not the individual.

The social relational definition of disablism I have used to inform my analysis so far, is useful in one respect because it highlights disabling barriers which operate at both the public and private level – for people experiencing mental distress, it is forms of psycho-emotional disablism which are likely to be the most problematic and disabling. For example psychiatric diagnoses of mental distress that are presented solely in terms of incurable/hopeless illness which necessitates drug treatment could be seen as forms of institutional psycho-emotional disablism; this is analogous to the surgical interventions carried out on people with physical impairments to 'normalise' them so that they can be accepted back into society (Hughes, 2005). The ways in which people experiencing mental distress are seen as discreditable solely on the basis of a psychiatric label could also be viewed as institutional psycho-emotional disablism.

However this definition of disablism which I am using here is still reliant on the presence of impairment – perceived/actual/past – which poses a problem for some such as Plumb (1994). The idea of impairment is obviously inappropriate for those people who see themselves as *being* different as opposed to a *having* a lack or illness. I think it is still true to say that strangers who shout abuse in the street (which I would usually term disablism) *are acting on* perceived/visible difference which is interpreted as impairment/illness. Although the terminology of 'impairment' and 'disablism' may not be right for people experiencing mental distress, nonetheless the same effects are at work and so a similar analysis may be useful.

The role of psycho-emotional disablism within a social model of madness and distress

One of the most significant points that Plumb (1994: 4-5) makes is that mental distress is analogous to disablism rather than impairment, because the roots of that distress are to be found within relationships with society rather than a chemical imbalance or other label attached to the individual. The research carried out by Beresford et al (2010) showed that a social model of madness and distress cannot be simply derived from a social model of disability. This is because many people experiencing mental distress do not consider themselves to have an impairment; or if they do, then it is seen as socially constructed, fluctuating – not as 'objective' and 'measureable' as the sensory and physical impairments associated with a social model of disability approach to discrimination and oppression.

However a social model of some sort is needed to explain the experiences of discrimination and oppression which are left untouched by medical model views of the lives of people living with mental distress. It is also necessary to take account of individual needs and social circumstances as financial and social resources (such as supportive family, employment, housing) as these will have a significant impact on how mental distress is experienced.

Leaving aside the definitional problem I discussed earlier associated with the use of the term 'impairment', I suggest that the concept of psycho-emotional disablism is still useful here – helping identify the roots of prejudicial attitudes and acts of invalidation experienced by people experiencing mental distress. Beresford et al (2010) conclude that a social model of madness and distress would be helpful in challenging internalised oppression – a form of psycho-emotional disablism which can happen when someone internalises the devalued and stigmatising messages about madness and mental distress.

> 'We are generally seen (even by ourselves?) as being at fault – 'not coping', 'not fitting in' of 'holding strange views' or 'behaving oddly'.
>
> (participant in Beresford, Nettle and Perring, 2010: 18)

Internalised oppression is insidious and difficult to counter because it largely acts at an unconscious level. As well as having a potentially damaging impact on someone's self-esteem and sense of self, it is likely to exacerbate the level of mental distress experienced by increasing fear and anxiety levels – another example of disablism and impairment interacting together. Beresford et al (2010: 32) call for more attention to be paid to helping people challenge their own internalised oppression through support from survivor-led organisations and movement. This peer support can model alternative (more positive/healthy) ways of being to those reflected by medical diagnoses and headlines in the Daily Mail.

New ways of being

If mental distress has its roots in relationships that the individual has with society and others (past/present), then there is also a need to recognise diversity of 'being' in the true sense of the word. Unfortunately our society is not very accepting of difference, as one participant commented:

> We all identify with each other, but we don't live in a society, despite the facts that we speak about individuality, we really don't like difference, do we? Anybody who's slightly different, reacts differently, get 'em out as quickly as possible, or try and change them.
>
> (participant in Beresford, Nettle and Perring, 2010: 26)

This is one of the points of departure from the social model of disability: whilst disabled people are fighting for inclusion into *mainstream* society, for others, it is the experience of being a round peg in a square hole which causes the mental distress in the first place (Plumb, 1994). Rather than being shaved down to fit the allotted hole, the fight is for a 'changed' society which recognises diversity

and allows for new/creative ways of being. In many respects disabled people are already doing this e.g. parenting a child with the assistance of a team of personal assistants.

Psycho-emotional disablism stifles these creative ways of being that provide validation rather than rejection of the person experiencing mental distress. So for example, one of the important aspects of the Hearing Voices Network is *listening* to what the voices are saying and making sense of the role they play in someone's past/present life rather than simply silencing these inner voices with drugs (Hornstein, 2009). Ontological validation is important to people experiencing mental distress, particularly when they may have experienced years of having their fears and experiences labelled as unreal fantasies, delusions or symptoms by 'experts' (Kristiansen, 2004).

I wonder if it might not be helpful to consider some of the contemporary debates going on in the neurodiversity movement. In many ways the ontological questions being asked are similar – the valuing of neurodiverse ways of being alongside the conventional neurotypically-informed 'norms' of being (Boundy, 2008). In both cases disablism emerges when the behaviour and actions of those who are neurodiverse or are experiencing mental distress 'clash' with societal norms of *behaviour* (which of course vary with culture/time/place). This is substantially different to the case of other groups of disabled people where the disjuncture is more connected with societal norms of moving/perception/comprehension – and where the removal of disabling barriers is 'common sense' (Plumb, 1994: 14) such as installing a lift, making information accessible and the provision of tactile pavement edges at street crossings.

Theoretical implications of mental distress for the disablism/impairment divide

Whilst there has been a general consensus that a social model of madness and distress has value in recognising the social forms of oppression – discrimination and prejudicial attitudes – that people experiencing mental distress face, the issue of 'impairment' never quite disappears. Some people who participated in the research reported earlier by Beresford et al were ambivalent about impairment – not liking the actual word but articulating a need for a term which was related:

> Well, I've always felt a bit uncomfortable about this, but it's there isn't it … I mean there's an impairment that's imposed on people in some kind of way, I suppose it is the equivalent, it's not a very good word, but it is the equivalent.

> (participant in Beresford, Nettle and Perring, 2010: 28)

This may have been due to a misunderstanding of what counts as disability or impairment – hence my use of the term 'disablism' from the start of this paper to describe social forms of oppression. However Kristiansen (2004) in her work with women experiencing mental distress in Norway has a problem seeing impairment as purely social because it denies the reality of the distress which does not originate from society/relationships, but is sometimes intrinsic to the experience of mental distress. Recognising that 'impairment' is not as straightforward as paralysed limbs or poor vision, instead she suggests that it might be more helpful to see disability and impairment as blurred rather than the dichotomy suggested by traditional social model approaches. For example, one woman in her study described how:

> People I know avoid me on the streets, look the other way … my doctor says I'm paranoid, oversensitive … I don't feel I am, but I just don't know … I don't think the medicine helps, but what else can I do?

> (participant in Kristiansen, 2004: 379)

In reality, what is seen as being caused by 'impairment' and what is down to 'disability' is unclear as the two threads are tightly interwoven, and the debates have little real-world relevance to the mental distress these women are experiencing.

The persistence of traces of 'impairment' in the accounts of those experiencing mental distress means that theoretical analyses need to include reference to impairment in some form or another. Elsewhere in this collection, Floris Tomasini discusses how mental distress can be seen as a direct challenge to the traditional dichotomies of mind/body, mental disorder/illness/distress, mental/physical dysfunction and he highlights the value of phenomenological approaches which recognise the interconnectedness of body-subject. Similarly Goodley presents examples of phenomenological approaches in disability studies which allow for theoretical analyses of the interconnections of body/society (see also Reeve, 2012).

Elsewhere I have suggested that one way of modelling the interconnections between psycho-emotional disablism and impairment might be through the use of a Möbius strip (Reeve, 2011). If a strip of paper has disablism written on one side, and impairment on the other, then joining this into a simple loop maintains the clear separation of disablism and impairment as typified by a conventional social model understanding of disablism. However if a twist is inserted before joining the ends of the loop then a Möbius strip is created which has a continuous single edge, and single face. If one follows the face around the Möbius strip, then disablism merges into impairment which merges back again into disablism – there is no clear dividing line. Whilst the Möbius strip is not without criticism – see for example the caveats listed by Elizabeth Grosz (1994: 210) who used the Möbius strip for a feminist exploration of the gendered body – it would nonetheless be worth considering the following questions:

- To what extent can a Möbius strip offer flexibility in how 'impairment' and psycho-emotional disablism are interconnected, as one can be at different points on the twisted loop?
- What can this offer the discussions of the part played by psycho-emotional disablism and 'impairment' in the experience of mental distress?
- Can it help resolve the thorny 'problem' of impairment?

However it should be borne in mind that although this kind of theorising supports the exploration of the continuum between disablism and impairment, it is still just another academic debate and potentially of limited use to those living in what Kristiansen (2004) calls 'mental health land'.

Concluding thoughts

As this is a piece of work in progress that illustrates the initial thinking I have done on the topic of psycho-emotional disablism in the lives of people experiencing mental distress, it seems most appropriate to finish with the questions that I am still grappling with since the symposium.

1. Do we still need some kind of signifier for 'impairment'? Is it possible to theorise mental distress without it and still take account of what Kristiansen calls the 'intrinsic' aspects of mental distress for many people?

2. Is it helpful to view the experience of mental distress as having different possible intersecting/fluctuating dimensions which include the following (in no particular order)

- Socially constructed aspects of impairment – for example the ways in which distress is seen as a difference to be chemically treated rather than understood as valid responses to trauma/life experiences.

- Psycho-emotional disablism – for example the invalidating responses of others based on cultural representations and myths about mental distress.

- Internalised oppression – psycho-emotional disablism arising from the internalisation of prejudices about mental distress. I have listed it here separately because in addition to the changes which need to be made at the society/media level to remove these prejudices, the survivor movement has much to offer in terms of modelling more positive ways of being in the world as a way of challenging this unconscious, but very damaging form of disablism.

- Impairment effects (or should this be psycho-emotional aspects of impairment?) which directly addresses the point made by Kristiansen not to ignore the real emotional difficulties which can accompany mental distress. Here peer support groups would be helpful in offering coping strategies, but some people may want medical interventions to manage this.

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Disability *and* distress: towards understanding the vulnerable body-subject

Floris Tomasini

This paper attempts to examine the following set of distinctions: body/mind; impairment/disability, mental illness/disorder and; the social/medical model of disabilities. While such distinctions are helpful up to a point, if pushed too far, they belie problematic dualisms that dichotomise: mind from body; physical and mental normalcy and deviancy from its psycho-social effects; an essentialist account of disability and mental illness from a phenomenology of disablism, vulnerability and distress and; a medical model or social model of disability from one that is fully embodied and integrated with our being-in-the-world.

Ultimately, as an alternative, we need non-reductionist ontology of embodiment, one that bridges body/mind/society. In doing so, this paper stitches together the gaps at the heart of the aforementioned dichotomous dualisms by exploring 'bridging concepts' that weave together a new way of understanding the body-subject and how it experiences and copes with its vulnerability in-the-world.

So, to overcome the dichotomy between the following concepts, there are 'thirds,' that ontologically bridge the gap

- Between mind/body: the body-subject is the ontological alternative to the mind/body problem (Merleau-Ponty, 2002). Instead of thinking of the 'mental life' of human beings as a separate 'substance' attached, as it were, to the body, subjectivity needs to understood as an 'emergent structure' (that is, as a body-subject). In other words, all our experiences and meanings which animate our lives are based on our active corporeal (and inter-corporeal) involvement in the world.
- Between mental disorder/illness: the idea of body-subject being mentally disordered is different from thinking of mental disorder as mental illness. Rather than seeing mental disorder as an essential mental dysfunction of the mind or the brain (mental illness), it can be seen as a primary *effect* of a mental disorder – of thought, intention, emotion and behaviour that cuts the disordered person off from ordinary social interaction. Mental disorder effects, whether mild or severe, have a bio-psycho-social character and can be understood as various mentally distressed or distressing behaviours, intentions. Moreover, they are phenomenologically rich/thick descriptions of a whole persons experience of the world and their interaction and is therefore quite different from an any essentially causal behaviour captured by mental illness (Matthews, 2007, Tomasini, 2013)
- Between physical impairment/disability: impairment effects introduce a bio-psycho-social character to having a physical impairment thus bringing talk of being embodied back into disability (Thomas, 1999). From an ontological perspective, this makes sense in terms of the body-subject and can be said to be a secondary effect of having a mental disorder.
- Between medical/social model of disability and disorder: a phenomenology of the vulnerable body-subject introduces a 'new grammar' of talking about how disability is experienced (Tomasini, 2013), filling the void between how body and mind becomes an object of normalisation (medical model) and/or should be a subject of social equality (social model).

Bodies, Minds and Body-Subjects

Mind body dualism at its roots is the view that mind is divorced from a material body with its own special laws. Positing that human beings are composed of two radically different and separate substances, mind and body, leads to many philosophical problems, not least how do they interact? One way out of the problem, is think of mental life as an emergent structure (rather than as a separate substance attached to the body) in its interaction with its environment. In other words, the

world is experienced in terms of how it is embodied as a whole, rather than breaking it back down into its constituent parts. Practically this means going back to how being-in-the-world is experienced, through our feelings, emotions, intentions and thoughts.

Mental illness, mental disorder and mental disorder effects

Merleau Ponty's conception of human beings as body-subject is a way of explaining mental disorder since it does not consider mind as a 'thing' constituting one part of a human being; rather, it takes human beings as wholes whose bodies are experienced as a means of existing in the world. From this point of view to think about human beings as body-subjects is to treat them not as minds loosely attached to biological organisms, or simply as biological organisms, but to affirm that they are human beings. In this sense, mental disorder must be defined as something different from the dysfunction of something called the mind or the brain (mental illness). In other words, we can define mental disorder as thought, or utterance, or emotions, or intentions, or behaviour which conflicts with human norms and cuts off the disordered person from ordinary social interaction. Furthermore, because mental disorder has social effects, it puts the emphasis back on its *distressing* experience: the distressing experience of emotion, intention and behaviour on self as well as others. This leads to a more compassionate treatment of the whole person in psychiatry and psychology.

Mental disorder effects can be the result of

- A primary mental disorder which first arises in how our thoughts, emotions, intentions and behaviours become disordered. These are hidden and are often, in common parlance, thought of as mental health issues. They can be classified as severe or mild, where mild affects ones failing to reach ones normal and expected mental wellbeing and severe affects 'mental health' and compromises reasonable quality of life.
- A secondary mental disorder which arises from a physical impairment.

Impairment, disability and impairment effects

Impairment effects introduce a bio-social character to having a physical impairment, thus acknowledging the direct and immediate impact that being impaired can and does have in the daily lives of disabled people (Thomas, 1999). Interestingly from an ontological perspective this fits in well with Merleau-Ponty's idea of embodiment and the body-subject. Moreover, impairment effects which are directly attributable to bodily variations have a neutral valence as regards certain physical restrictions that many take for granted e.g. an amputee may not be able to mount a series of steps without the use of a functioning prosthetic limb. This may cause them mental distress, especially when their thoughts are disordered and sensations about having a limb that is not there (a phantom limb) get in the way of using a prosthetic. However, in such a case disordered thoughts may be a natural by product of having an amputation and will be only become oppressive, if that person cannot adjust to being an amputee. More complicated still are cases where third parties help to co-construct, how one may psychologically cope with an impairment effect. For example, if a fully functioning amputee who has physically and psychologically adjusted to a prosthetic, is discriminated against by people with power and authority, because they are not seen as fit as an able bodied person – to be a postman for example – then this constitutes disablism. Any oppressive feelings that arise from this experience, are in part caused by the attitude of others in society, and are therefore introjected. In short, these are distressing forms of 'psycho-emotional disablism' that are significantly complicated by the attitude of others.

Medical, social and integrated models of disability

The medical/individual model is often characterised by an essentialist notion of 'illness' that is normatively evaluated as deviant to a supposed social norm. Disability and or mental illness is therefore, perceived as unavoidable physical or mental dysfunction. Whereas this might not be a problem if such judgments retained value neutrality, the evaluation of illness (mental or physical) is often seen as what is essentially wrong with the individual. This can lead to further discrimination

between what is and what is not publicly acceptable, often stigmatising those that are unfit (especially, if that unfitness is perceived as a mental illness). What is lacking in such a model is that does not treat, embodied experience of the whole person.

The social model of disability has, in many ways, addressed some of the glaring problems with medical model, especially in its inherent failure to be socially and politically egalitarian; where instead of seeing the wrongness as lying with the individual, it is laid at the door of society and its failure to accommodate difference. However, it too, has failed in addressing embodiment and the full experience of how impairment and mental disorder is lived.

Between medical/social model of disability and disorder: a phenomenology of the vulnerable body-subject introduces a 'new grammar' of talking about how disability is experienced (Tomasini, 2013), filling the void between how body and mind becomes an object of normalisation (medical model) and/or should be a subject of social equality (social model).

Vulnerability is closely linked to the narrative of distress. It transcends the neutered causal and implicitly judgemental classification of mental illness, for the richer experience of whole persons who experience distress - the vulnerable are both distressed by themselves and distressing to others. How this understood and coped with is a better way of dealing with mental disorder, whatever it cause.

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Recovery as a process of decolonisation? History, politics and experience

Brigit Morris Colton

Abstract

In this paper, I will outline a brief history of the recovery movement and consider how postcolonial critique might usefully contribute to debates between survivor activists and disability studies about how spaces for alternative knowledges and practices for dealing with psychosis can be made within/without the British Mental Health system. I trace how the concept of "recovery" arose out of consumer/user activist led response to the problem of psychiatric knowledge which uses a harmful diagnostic and chemical framework to subjugate psychiatric patients. Following Kristjana Kristensen (2004), I consider psychiatry as a 'colonising knowledge,' exploring how recovery might relate to notions of "decolonisation". In the paper, I will relate notions of colonisation/decolonisation to questions of self-representation, and the importance of critically examining who gets to speak about recovery, and which recovery stories count. This paper draws on empirical research within an NHS arts for mental health service, focusing on the struggles within this service to articulate their non-clinical recovery-orientated practice in clinical terms in order to maintain funding.

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Sorting trucks and going forth: Service provider and service user discourses of recovery.

Tony Sparkes

Introduction

Contemporary understandings of recovery[1] are held to have emerged out of the growing civil rights movement of the 1960's and 1970's concerning the marginalisation of disabled people within advanced capitalist societies (Allott, Loganathan and Fulford, 2002). Ralph (2000) suggests more recent notions of recovery have emerged out of the 'lived experience' writings of North American service users from the late 1980's onwards (for example Deegan, 1988). Anthony's much cited (1993) paper is argued to represent one the first to be articulated from a non-consumer perspective (Ralph, 2000). International interest in the concept of recovery lead Davidson and Roe (2007: 460) to claim that *'The unprecedented advance in US policy is reflective of an increasing global interest in recovery as the expectation for people living with mental illness.'*

Underpinned by New Labour's modernisation agenda (DoH, 1998; 1999; 2000) ideas of recovery were introduced into mental health policy in England as its 'vision' for mental health care (DoH, 2001)[2]. Assisted by the National Institute for Mental Health (NIMHE)[3] New Labour's administration never actually defined what recovery meant, opting instead for multiple meanings and a framework of principles and values directly imported from the Ohio Department of Mental Health in North America (NIMHE, 2004; 2005). Despite such conceptual vagueness, recovery progressively found residence within professional thought and practice: for example; Psychology (Kinderman and Tai, 2008), Social Work (Ray *et al.*, 2008), Mental Health Nursing (DoH, 2006) Occupational Therapy (College of Occupational Therapists (COT), 2006) and Psychiatry (CSIP/NIMHE, 2005).

The incumbent Coalition government however did introduce a definition (DoH, 2011) and drew upon Anthony's (1993) meaning[4]. However, the broader literature suggests that recovery is a contested concept (Bonney and Stickley, 2008; Pilgrim, 2008, 2009; Spandler *et al.*, 2007; Spandler and Calton, 2009). In an attempt to explicate the meaning of recovery beyond its common usage, Roberts and Wolfson (2004) suggest that:

> 'Within the recovery literature it has been has been variously used to mean an approach, a model, a philosophy, a paradigm, a movement, a vision and, sceptically, a myth (Whitwell, 1999).'

> (Roberts and Wolfson, 2004: 38)

Such is the lack of consensus regarding what recovery means, Davidson *et al.*, (2005) suggest that:

> 'The only thing about which most stakeholders seem to be able to agree, in fact, is that the notion of recovery has become the focus of a considerable amount of confusion and debate between and among various constituencies within the mental health community.'

> (Davidson *et al.*, 2005: 480)

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[1] Present-day notions of recovery are considered to have historical precedents in the Tukian practice of lay moral treatment at the York Retreat (Roberts and Wolfson, 2004; 2006) and medical moral treatment at Pinel's Bicêtre and Salpêtrière hopsitals in France over 200 years ago (Fardella, 2008). See for example Charland, (2007), Borthwick *et al.*, (2001), Digby (2001) and Scull (1979) for discussions regarding moral treatment.

[2] Although the term recovery appears in the DoH (2001) document, evidence suggests that the concept was attracting interest within the UK during the early/mid 1990's, pre-dating New Labour's election to office in 1997 (for example NIMHE, 2004)

[3] NIMHE were inaugurated in 2001 under New Labour's mental health modernisation programme.

[4] Again, this is definition taken from North America and I include this in appendix I for reference.

The current paper is written in context of a broader doctoral thesis, the motivation for which arose from the author's fieldwork experience as a mental health social worker and local authority support services manager. It was observed that outside of central government policy rhetoric, neither service providers nor service users used the word 'recovery' in their working practices or daily lives.

Objective and methods
Objective

The objective of the broader study sought to address the following question:

> Do service users and service providers draw on discourses of recovery? If so how and in what ways? If not, what other discourse are drawn upon to make sense of experiences? And what are the implications of this for all stakeholders in the mental health community?

This paper orientates to the first of the above research questions and reports on a reading of service provider and service user talk about recovery.

Method(s)

Following research ethical approval (REC ref: 10/H1015/33) a single-site ethnography was conducted between July 2010 and February 2011, within a jointly run Local Authority Social Services/National Health Service establishment in the North-West of England. The agency provides 'social inclusion and recovery services' in context of its wider portfolio of mental health care provision to the local population. Participant observation, documentary analysis and semi-structured interviews with service providers (n=9) and service users (n=9) indicate the broad qualitative research methods used[5]

Participants
Service providers and service users were opportunistically recruited and invited to participate in one semi-structured interview at around 6 months into the fieldwork. Service providers were recruited from professional and non-professional backgrounds and were all based at the above site.

Data Analysis
The findings presented here are derived from the textual analysis of transcribed audio-recordings of semi-structured interviews between the researcher (author) and service providers and service users. Advised by social constructionist theorising (Berger and Luckmann, 1966; Burr, 2003; Gergen, 1985) the analysis worked from poststructural sensibilities which acknowledged Foucault's (1972: 49) notion that discourses are *'practices that systematically form the objects of which they speak',* whilst at the same time appreciated the improbability of a definitive Foucauldian analytic method (Graham, 2005). Thus the analysis presented here draws upon a version of analysis that is informed by a broad Foucauldian*istic* approach suggested by Willig (2001). Taking 'recovery' as the discursive object, the analytic process discussed here first involved an iterative reading of how and in what ways recovery was discursively constructed within the text and then moved to locate these within wider discourses. Consideration was given to the plausible effects within the opening up and closing down of talking about recovery in particular ways, including the various subject positions afforded (Davies and Harré, 1990).

Findings
The title of this short paper is intended to capture the broad spectrum within which participants talked about different versions of recovery; from on the one hand a mechanistic 'sorting of trucks', to on the other hand a sense of 'going forth' into the world as a person with agency. It is perhaps salutary to note however that within all interviews while the word 'recovery' was never introduced

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[5] A more detailed account of the research methodology and methods used is available upon request.

by any of the participants, various and nuanced discourse of recovery were evident. I first introduce service provider talk of recovery followed by service user talk of recovery. There is no privilege to this and the order is merely for clarity.

Service provider

Six distinct discourses of recovery developed around my reading of transcribed interview texts. I shall introduce these as:

A. Division of labour.

    a. Recovery was talked about as something that denotes a specialism within broader mental health services, and inhabited by particular groupings of mental health practitioners under the heading of a 'recovery service.'

    b. Recovery was articulated as an outcome or product of mental health work.

B. Optimistic turn

    a. Recovery was discursively constructed as synonymous with future-oriented concepts such as 'hopes' and 'aspirations.'[6]

    b. Related although distinct to the above, recovery was spoken about as a personal 'goal' that emerged as a consequence of identifying 'hopes' and 'aspirations.'

    c. Talk of recovery was used as a metaphor for a personal sense of physically and emotionally 'moving on.'

C. The Independent self

    a. Contested versions talked of recovery as a measure of independence, often in context of the particular service received. Some service providers talked of recovery as something associated with more 'dependent' services (in-patient status for example) whereas others talked of recovery as more associated with service users who were about to be discharged from mental health services.

D. Life

    a. A version of recovery was constructed as something that we are all involved with. A multiply-versioned subjectivity that is as varied as there are people.

E. Resistance

    a. Talk of recovery was actively and directly resisted through language that explicitly restricted engagement with the word, or truncated the word to a level of the unspeakable (for example the 'R' word).

    b. Talk of recovery was actively and indirectly resisted through the mobilisation of discourses that worked to silence its possibility outside of the discourse used to utter its name. For example, a division of labour discourse allowed talk of recovery but only in so far as it could then be immediately closed down as the legitimate concern of another, 'specialist' recovery service.

F. Medical

    a. Recovery as mechanical

    b. Recovery as sounding ill

    c. Recovery as clinical

    d. Recovery as cure

    e. Recovery as relapse

    f. Recovery as focussing upon illness

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[6] As part of the initial assessment process the research site routinely asked service users about their recovery goals, their hopes and their aspirations.

g. Recovery as being better

h. Recovery as being normal

i. Discursive constructions of recovery within the text (a-h above) that drew upon a medical discourse were most frequent and most varied.

Service user

My readings of transcribed service user interviews suggested six discourses of recovery. I shall introduce these as:

A. Rescue

    a. Service users talked about recovery as a form of rescue, as a passive rescuee from danger or crises.

    b. In a different way to the above, recovery was also talked about in terms of as an active rescuer of the self from unhelpful behaviours

B. Pharmacological

    a. Service users constructed a version of recovery that made connection to the effects of medication.

C. Control

    a. Talk of recovery was articulated as a state of being in control of one's life

D. Return

    a. Contradictory to ideas of optimism, recovery was constructed as a restorative return to something previous

E. Resistance

    a. Recovery was talked about as something not particularly relevant and coping rather than recovery was a better term

F. Living with what you've got

    a. Simply 'getting on' with one's life.

Discussion

As Plumb (1994: 15) suggests, there is a lack of consensus as to whether (psychiatric system) survivors consider themselves to *'have a physical impairment, hidden or otherwise.'* Whilst I do not discount this to be an important conceptual point, I shall orientate this brief discussion to the *attributional* notion of impairments as I feel this to be a central issue raised in Plumb's (1994: 15) paper. Thus, although ideas of 'impairment' may hold greater currency within the disability movement, people experiencing distress are exposed to potentially oppressive and hurtful experiences through the *inference* of hidden impairments which are attributed to them through a narrow medical lens that privileges ontological 'truth claims' which medicalises human distress as mental *illness*.

I would argue that any disruption to the process of *attribution* of impairment would be helpful. With reference to the broader recovery literature, service user ideas of recovery may be best suited to this challenge as it does not necessarily require the displacement of the medical model, nor does it necessitate the adoption of the social model. The shift could be best described as a movement from patient-hood to person-hood (Campbell and Shraiber, 1989), and a reclaiming or revalidation of the individual through the process of what Deegan (1996: 92) describes as *'becoming more deeply, more fully human.'*

The findings reported here would attest to a version of recovery that predominantly drew upon a medical discourse. Framing ideas of recovery in this way tended to draw upon linguistic resources which constructed versions of recovery that appealed more to a biologically determined,

individualised and deficits based arrangement nearer to a medical model. While I do not claim that the medical model to be less than useful in aiding an understanding of mental distress, the findings reported here suggest that its privileged position occludes the potential for alternative versions of recovery to flourish and create other possibilities of understanding distress.

Conclusion

Although drawing heavily upon a medical discourse service provider and service user talk of recovery appears to affirm ideas that the concept is polyvalent (Pilgrim, 2008; 2009) with multiplicity of meaning scattered across personal and temporal instabilities. Such variability in meaning may be turn out to be a strength of the concept rather a weakness and offer a fruitful way of exploring ideas of distress and disability.

Appendix I

Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.

(Anthony, 1993: 527)

Tony Sparkes is studying for a PhD in the Department of Applied Social Science at Lancaster University.

Three relapses in one year: My story of recovery with bipolar disorder

Kirsty Stevenson-Turner and Debbie Mayes

Debbie's story

I have a long history of mental health problems. I am bipolar. I've had lots of episodes, mostly depression but sometimes mania or hypermania. My first hospital admission was when I was 26. Since then I have had 8 inpatient admissions, the last one was 5 years ago and I've had plenty of episodes in-between and since.

This is what my bipolar life chart looks like[7]:
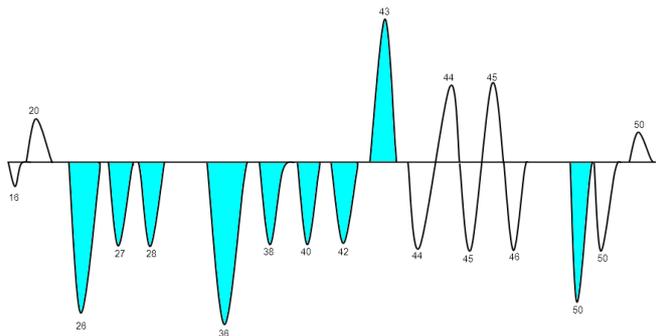
When I first did it I was shocked. I thought that it looked like the life chart of someone really ill, who was never in recovery and certainly who didn't work. The last 3 episodes you can see on the chart took place over the past year. If I was a participant in a clinical study and had 3 relapses in one year, it would be reported that for me the intervention had been unsuccessful and I would not be classed as being in recovery. Throughout my life though, in-between each of my episodes I have got back to work, or if not immediately to work, to a meaningful day with exercise, art and social life.

To me, recovery is about hope and optimism and picking yourself up after you've been knocked down and keep picking yourself up, not letting yourself stay down.

Overall, I think I will always be in recovery. I will never be recovered, and three episodes in one year is manageable providing I get on reasonably well in between – and I do! So 3 episodes in one year is my recovery journey."

So how did everyone in mental health come to be talking about 'recovery'? And how did we arrive at a point where increasing numbers of service users have come to feel that their definition and experience of recovery bears little, if any, resemblance to definitions used by mental health professionals?

Origins of the Recovery discourse

' Recovery' is a discourse which has become incredibly powerful and ubiquitous in relation to 'mental health'; found everywhere; in Service User/Survivor narratives, policy documents, agendas for service provision and in research, so much so that it is hard to believe that the notion of 'mental health' recovery was barely even contemplated until relatively recently.

Until relatively recently, recovery from a mental health condition was not considered possible. Once labelled as 'mentally ill' a person was encouraged to accept their fate and expect and hope for little

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[7] Mood charting is a popular tool used and promoted by 'Recovery approaches' within NHS Mental Health Services. A Bipolar Disorder life-chart is designed to systematically capture data about a person's mood over the course of their 'illness'. Hypomania and mania are charted above the mid-point horizontal line which represents the baseline (euthymia, neither depressed nor hypomanic or manic) and depression is charted below this line, creating a visual picture of mood fluctuations over time.

more than the possibility of symptom relief, if the right combination of medications were found. Numerous Service User/Survivor accounts recall the experience of feeling they had been effectively written off by mental health services, sent away to contemplate a bleak future with no possibility of wellness and certainly no hope of making a recovery.

Service User/Survivor movement

However, the 1980s saw the beginnings of a significant sea change in the approach to recovery and this change is broadly accepted as having begun with the publication of a number of prominent Service User/Survivor accounts describing personal experiences of managing symptoms, of getting better and of regaining a sense of personal identity, (Wallcraft, 2010)

'Recovery' became reconceptualised by prominent Service User narratives, such as that of Patricia Deegan, a Clinical Psychologist and mental health activist, who in 1988 described the significant parallels she found in her recovery journey through mental distress with the recovery experiences of her friend with quadraplegia . In so doing she argued that recovery should be seen, not as an outcome, an end point at which the person can be deemed symptom free and returned to their previous state, but as a change in attitude, away from passive, helpless acceptance of a mental health diagnosis towards a desire to live a full and meaningful life and a positive approach to the limitations of the condition.

On discovering similarities between her own recovery journey and that of her physically disabled friend, Deegan writes of the 'paradox of recovery':

> Recovery does not refer to an end product or result. It does not mean that my friend and I were "cured". In fact, our recovery is marked by an ever deepening acceptance of our limitations. But now, rather than being an occasion for despair, we find that our personal limitations are the ground from which spring our own unique possibilities. This is the paradox of recovery i.e. that in accepting what we cannot do or be, we begin to discover who we can be and what we can do.

> (Deegan ,1988)

The term 'Recovery' came to signal an alternative agenda in mental health, a paradigm shift away from what was seen as the limiting and oppressive nature of Psychiatry and the Medical model, with its rigid definitions and emphasis on symptoms, towards an approach which viewed recovery as a personal journey, a lifelong process, fraught with struggle and setbacks, but which also offered the possibility of hope for a better future and the promise of new possibilities.

First person accounts of recovery such as Deegan's began to be supported by the publication of clinical research evidence, such as Harding et al's 1987 Vermont longitudinal study of persons with severe mental illness which contrary to the prevailing view of the mental health profession demonstrated that the course of severe mental illness was not an inevitable deterioration, and that for a significant number of people with diagnoses of severe and enduring mental health conditions a return to a full life was absolutely possible. This represented the beginning of a shift in perspective and approach.

The professional psychiatric community and mental health policy makers began to take interest in the concept of recovery, particularly following the publication of Psychiatrist and academic, William Anthony's landmark paper, Recovery from Mental Illness: The Guiding Vision for the 1990s which drew upon service users experience of recovery and again, supported the views of service user writers such as Deegan that as with physical illness, someone with mental illness could recover without their condition being "cured**".**

Anthony stated that:

> Recovery is a multi-dimensional concept: there is no single measure of recovery, but many different measures that estimate various aspects of it. The recovery vision expands our

concept of service outcome to include such dimensions as self-esteem, adjustment to disability, empowerment and self-determination

(Anthony 1993)

Whose Recovery is it anyway.....?

Since the 1990s 'Recovery' has been the 'buzz word' in mental health. The majority of mental health organisations have sought to define recovery and adopt it as part of their 'vision'. 'Recovery' dominates the agenda of mental health research, 'Recovery Principles' underpin the framework for policy development and numerous 'Recovery models' have been developed. In recent years however, there has been something of a backlash against the Recovery Approach. Voices from the service user and survivor movement and also from within the mental health professions have begun to raise concerns about how the original concept of recovery has been hijacked by the mental health profession and diluted and subsumed within 'Recovery model' and 'Recovery Programme' approaches, whose perspective is limited and limiting and which, they argue, are being used to serve political ends in conflict with those sought by the original Recovery movement. Indeed some prominent Service User writers and mental health campaigners such as Jan Wallcraft and Pat Bracken have sought to distance themselves from the recovery approach because they consider that it fails completely to recognise the complexity of the subjective aspects of lived experience of mental distress.

An internet search on mental health recovery also reveals the increasing presence of a significant Recovery Resistance movement, evidenced by anti-recovery Facebook pages and highly critical comments on service user and social care websites.

> Recovery is now all about getting people into work at any cost – even to the detriment of their health, wellbeing and in some cases lives. Maybe we need to think about if the system needs reviewing rather than trying to put square pegs into round holes .

> (Service user – Psychminded.co.uk)

> I recently heard colleagues talking about 'recovery – how not to relapse'...this would seem somewhat contradictory and highly revealing about where things are really at in frontline mental health services around recovery. In the UK recovery does seem to be the latest buzz word, serving a range of political and financial expediencies for some people."

> (Project Co-ordinator – Mind website)

Much of the current resistance to the recovery approach from service users appears not to be with the concept itself but with its narrow definition and application. It would seem that despite concerted efforts by all involved in mental health services to be seen to embrace the concept, in practice recovery has long presented a difficult challenge to those working in this field when assumptions, language and practices remain deeply entrenched in the Medical model. Deegan sums up this contradiction neatly when she writes:

> Perhaps the phenomenon is elusive precisely because it is so fundamental. Perhaps it is because the recovery process cannot be completely described with traditional scientific, psychiatric, or psychological language. Although the phenomenon will not fit neatly into natural scientific paradigms, those of us who have been disabled know that recovery is real because we have lived it.

> (Deegan 1988)

Given the fluid, diverse and subjective nature of the recovery process, attempts to measure it are intrinsically fraught with difficulty, particularly given that mental health professionals, practitioners and academics operate within a context where evidence based interventions and cost-effectiveness criteria dominate.

There is no simple solution to the challenge of 'Recovery', but from a service user perspective, the answer surely lies in returning to the original spirit of the Service user/Survivor movement who first brought the concept to public attention. What is needed, in Psychiatry, in Research, Policy and Mental Health practice is an approach which recognises that the most valuable sources of insight and knowledge into recovery are those who live it on a day-to-day basis; an approach which begins and ends with the individual service user, an approach which can recognise that 3 relapses in one year can be a legitimate and indeed a positive part of a person's recovery journey.

Pottery as a metaphor for Recovery:

We will end, as we began with Debbie's story**.** As Debbie describes in her story, a fundamental part of recovery is about a willingness to take on the fight, to get back up whenever you experience a set-back and to strive for a life which has meaning beyond a mental health diagnosis. For Debbie some of this meaning emerged during one period in hospital where she discovered her talent as an artist through an initial encounter with pottery.

 Pottery has since become for her a metaphor for recovery:

> One of the great attractions of pottery was that you could always begin again. I loved the unending quality of the clay and couldn't get over the way in which I could take a dried pot, soften it down, wait for it to get firm and then knead it through to be used again. Clay seemed to me to be like a cat with nine lives. What a lovely quality to have, the ability to survive no matter what. No wonder I always felt that clay was so alive! Thinking back on this now, pottery seems like a metaphor for recovery. After illness, I have to take a break, allow myself to get well and then begin again, perhaps in a new direction.

> When I left hospital, I joined a community pottery class, day time adult education classes until I reached the point where I felt confident enough to return to work. In those early days the mental health professionals advised against my returning to work and since then throughout my life that has been a pattern, that I want to return to work and the professionals advise against it because they don't feel that I've recovered sufficiently....Now I'm not good at doing nothing, it makes me feel worse so I get involved in things such as a community mental health art project that I belonged to for 10 years when I was living in London. This was something that could be quite stressful and challenging but that was also wonderfully creative and satisfying. It was hard for the mental health professionals to accept that I was putting myself under stress but that there were pay offs for me and that this was my route to recovery.....I see recovery as about achieving a balance in your life – enough stimulation balanced against the necessary stress that any worthwhile endeavour will involved."

Kirsty Stevenson-Turner and Debbie Mayes are both Service User Researchers in the Spectrum Centre at Lancaster University.

Complex trauma: A composite case study exploring responses to complex trauma across a lifespan

Shelley Briggs and Fiona Cameron

The following composite case study is based on the practice experience of the authors, Shelley Briggs (working with First Nations communities in remote northern British Columbia, Canada) and Fiona Cameron (working with women with forensic histories in secure and community settings). While the authors experience was in very different settings, they discovered a commonality of experience, observing that many of the people with mental health issues, women in particular, experienced repeated trauma, alongside discrimination and oppression. Societal and professional responses to the behavioural and psychological reactions to these traumatic experiences, has been on the whole limited to medicalising and criminalising the individual.

Working in practice settings where those experiencing complex trauma were accessing a number of services but these services not really addressing the issues can be difficult for the practitioner. Both authors found that working with people with severe and prolonged traumatic experiences, and behaviours that resulted from the trauma, combined with the lack of services addressing these issues, had an impact on the authors. Working on this paper has been inspired by the work and the need to address the links between trauma and mental health, for improved services and for the support of those practitioners providing the service.

Although 'containment and emotional labour' (Gregor, 2010) or 'working with emotion' (Thompson, 2009:91) has been acknowledged as a significant part of direct social work practice, however, according to Cunningham, 2004; Courtois, 2002 and Shackelford, 2006 as cited in Newell, and Gordon, 2010 'the emotional and psychological risks associated with providing direct social work services to vulnerable populations have been largely overlooked in social work educational curriculum and agency training.

Case Study

Sally is a 38-year-old woman, living in a small community with her husband and adolescent son. Sally was diagnosed with drug induced psychosis in her earlier thirties and is now under the care of a psychiatrist and her local mental health team. Her symptoms of auditory hallucinations and thoughts of persecution are managed by medication, which makes her feel groggy and flat. She spends most of her time at home in front of the TV with the occasional night out at Bingo.

The community and family environment are significant with Sally coming from an area with limited job opportunities where low socio economic status has lead to a significant community reliance on welfare or crime. Incidents of domestic violence and problematic alcohol and drug use are high in the community.

In Sally's family there has been significant trauma with a series of alcohol and drug related accidental deaths and suicides, sexual abuse and domestic violence. Sally has witnessed and experienced domestic violence by her father and brothers, and was sexually abused at an early age by her uncles, grandfather and later her brother. Sally's mother had similar experiences in childhood and was depressed and anxious. She was unable to protect or support Sally just as her own mother had been unable to protect Sally's mother from her violent father.

It appears to the authors that this is an example of intergenerational or generational trauma. Doucet and Rovers (2010) define this as a 'secondary form of trauma that results from the transfer of traumatic experiences from parents to their children' (ibid: 94). The authors would argue that from their experience intergenerational trauma has a major impact on the individual, families and communities. In Sally's case the intergenerational trauma and level of violence in community support the proposition that violence towards women becomes normalised behaviour in some communities.

Sally was quiet and withdrawn and struggled to concentrate in school. Her dissociation related to the abuse and trauma was not recognised by the school and Sally was labelled as difficult. This was compounded by the fact that Sally was only allowed to go to school intermittently as her had to care for her mother. Sally enjoyed going to school but with lack of support to manage her difficult feelings, she moved from withdrawal to aggression and was expelled from school after throwing a chair.

These early responses to trauma resulted in community/cultural rejection on both sides and Sally leaves the community at age 14. She does not fare well, using drugs and alcohol to manage uncomfortable feelings; she works on the street and is in a violent relationship.

There is a turning point when Sally is given support and recognition from a refuge. She manages her own flat for short while but a reduction in support and isolation, increase anxiety and lead to new experiences of trauma as society rejects her. Negative beliefs of self lead to depression and a serious overdose attempt that results in having her stomach pumped and hospitalisation. The MHA 1983/2007 is used to administer forced pharmacological interventions; this is her first contact with mental health services.

Returning to her community, feeling rejected, angry and anxious, as memories of prior trauma increase. She copes with substance use and gambling and meets her husband, who is controlling and violent. This further traumatises and reinforces suspicions of others. Mental health services re-diagnose her as having borderline personality disorder. (BPD)

The numerous previous diagnoses, such as depression, BPD are clearly a timeline of the symptoms and responses to trauma at different times and in different contexts. Sally's responses vary from hyper-vigilance which reinforces her paranoid thinking to repeated self- exposure to high risk situations/relationships. A chronic lack of self- esteem and confidence make it very difficult to escape from abusive relationships.

The diagnosis of BPD is not surprising giving the relationship between trauma and emotional regulation. Marshall- Berenz, et. al. (2011) completed a study looking at the role of Post-Traumatic Stress Disorder and Borderline Personality Disorder, and emotional deregulation. Their studies found emotional deregulation was increased with PTSD symptoms.

The authors have experienced in practice this changing presentation of 'symptoms' that they now view as adjustments to trauma. A useful way of exploring this might be using the concept of complex PTSD (CP). This is 'a term that has been used to refer to a symptom constellation often seen in individuals who have experienced long-term and multiple trauma experiences – either in childhood or in adulthood' (Herman, 1992)

The authors would argue that services generally do not view Sally's symptoms as a psycho-emotional adjustment to CPTS, but would judge her negatively on the basis of her presenting 'behaviours'. It has been established in various research that the diagnosis of Borderline Personality Disorder, has a very negative stigma attached which impacts on the delivery and attitudes of those in service provision. (Bodna et al 2011, NIMHE 2003, Commons Treloar and Lewis, 2008)

As Reeves (2004) identifies, these negative responses via social interaction with others (family, friends, strangers and those within professional services) can be as disabling as structural barriers. This example of psycho-emotional disablism perpetuates the vicious circle of multiple trauma and presenting behaviour.

The birth of Sally's son is very difficult and she struggles with the hormonal changes and feeling of violation. Essentially she is re-traumatised. Violence in her relationship has decreased but contact with family rekindles traumatic memories. She feels unable to support or protect her son and is very suspicious of others. She copes by drinking more. When her son is aged 5 she is hospitalised again and diagnosed as having a drug induced psychosis. The development of psychotic symptoms would

appear a logical progression of the ongoing exposure to trauma. The interplay between psychosis and trauma is multi-faceted, explanations have included physiological responses to stress.

Read et al. (2001) outline a 'traumagenic neuro-developmental model of schizophrenia' where the activation of the hypothalamic-pituitary- adrenal (HPA) axis is one of the primary manifestations of the stress response. The release of cortisol and dopamine and dampening of the negative feedback system as a consequence of prolonged or severe exposure to stress/abuse in childhood, they conclude can result in brain 'abnormalities' that can persist into adulthood, which highlights the role that environment has.

The authors concur with the following statements made by Read, et al. 2006: 36;

- Individual 'psychotic symptoms' are situated on dimensions of understandable, ordinary psychological processes which are reactive to past and present life events and circumstances
- 'Symptoms of psychosis' have psychological meaning, and they can serve a function, such as defending against intolerable feelings and memories
- The relationship between childhood events and adult outcomes involves a complex set of (often reciprocal) interactions between a large number of personal and social mediating variables.

One of the components of this interplay between psychosis and trauma is the level of trauma. In Shevlin et al's research in the UK and America (2008) they contend that 'multiple types of trauma significantly increased the likelihood of psychosis' p.197.

Sally's trauma history starts in childhood with intergenerational and community trauma, personal childhood traumas, followed by a series of traumas in adulthood. The trauma is further compounded by contact with services, and the psycho- emotional disablism experienced by this type of service users, who are the lowest on the hierarchy of disablism (Reeve, 2004). This multiple faceted trauma does not seem to be captured in the term multiple traumas and the author's would suggest complex trauma captures the dynamics of the traumatic experience across the lifespan better.

This raises the question around the interplay between, trauma, retraumatisation and PTSD for the individual. Janowski, et al. 2009 have provided an interactive model depicting the interplay between PTSD, trauma and severe mental illness.
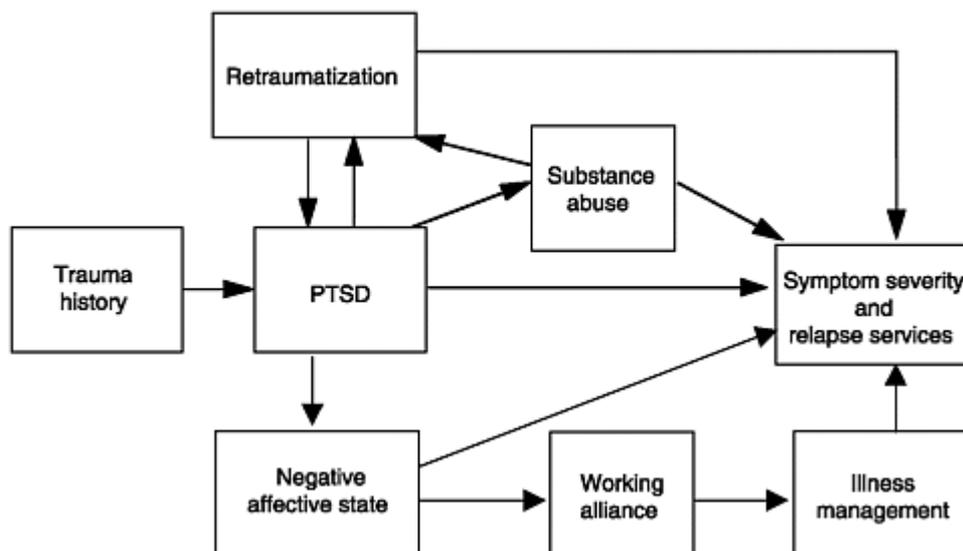

(Janowski et al, 2009, p. 81)

Sally has experienced complex trauma which is multi- faceted and interplays between the trauma and her adjustments to trauma.

The authors believe the above model could be further extended to reflect the layered nature of (re) traumatisation, for example, the role that intergenerational trauma plays in terms of influencing the severity of symptom experience. This model deals primarily with the individual and their interpsychic responses to complex trauma. This model does not take into account the interplay between, environment; society; community and the inter and intra psychic responses to complex trauma. To address this interplay the authors have conceptualised the interplay between individual adjustments to trauma, reinforcing negative interpersonal interactions, local community responses, service responses and wider societal responses as a complex, interactive interplay with layers like an onion (see Trauma Adjustment Interplay on next page)

In the Trauma Adjustment Interplay the authors identify various layers of adjustment that are discussed under the following headings. These are not distinctive areas of responses as represented in the model by the multiple layers between the different concentric circles and there are clear interactions and commonalities between the different layered responses to trauma. There is an interplay between psycho social disablism and all of these layers of trauma response.

Trauma Adjustment Interplay
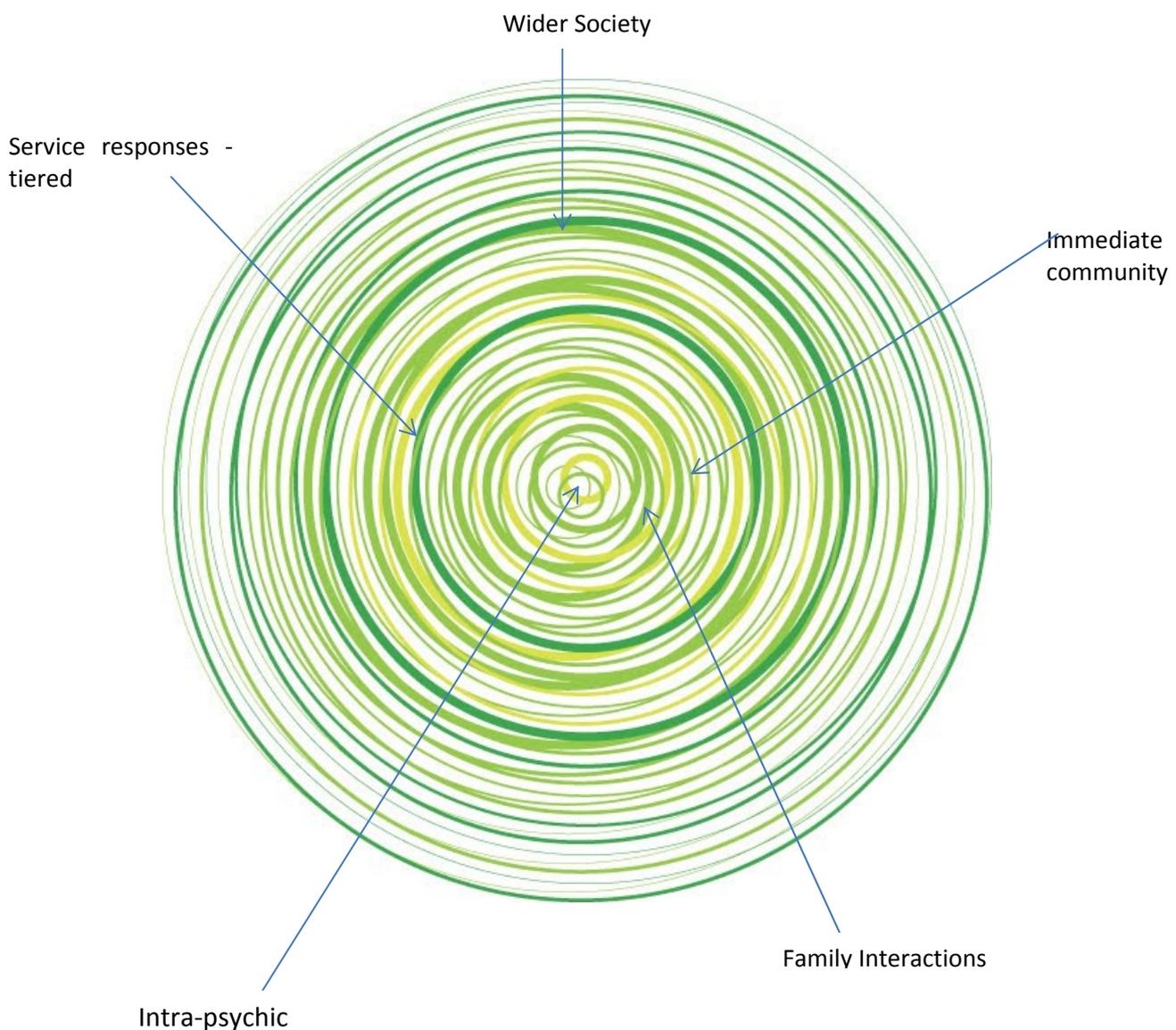
The Trauma Adjustment interplay model builds upon the bio-ecological theory developed by Bronfenbrenner in 1972, 1975 and further developed throughout his life time until 2004. This confers upon those involved in child development the edict that this must take into account the developing child's context within their microsystem, mesosystem, exosystem and macrosystem.

Intra-psychic responses to multiple traumas

At this stage there can be reference to psycho dynamic ideas around coping strategies and different defence mechanisms such as dissociation, denial and suppression. Responses will depend upon variables of trauma exposure such as age of onset of CSA/CPA; severity of abuse, length of exposure, level of hostility/violence involved; responses to disclosure, whether the victim blames perpetrator or self. (Morrison et al, 2003) The role of schema and schema therapy are relevant in the interplay between intra psychic responses and external responses. Possible schema's that develop as a result of complex trauma include; I am unlovable; world is an unsafe place; do not trust anyone. (Young, J. 2003)

Family Interactions

There are a wide range of variables in this layer, with potentially positive and negative impacts on trauma adjustments, depending on the family dynamics and the interplay between the other layers of adjustments.

A key area of consideration for this case study of complex trauma is the intergenerational trauma. Doucet and Rover's (2010) discuss the two pathways of intergenerational trauma; direct and indirect. Direct transmission of trauma is via unconscious channels of intra psychic influences and styles of communication versus the indirect transmission via parenting styles or family interaction. This can lead to parents unable to parent, the child caring for the parent and the child absorbing the unresolved emotional burdens of the parent, as exemplified by Sally's case study. (Doucet and Rover, 2010, p 96)

Immediate Community responses

Within the immediate community the authors are referring to the community that has the greatest personal connection, influence and establishment of norms. This may not be a geographical based community, and like the family can have a positive or negative impact on the trauma adjustment.

Persistence of behaviours such as abuse and violence reinforce the intra-psychic response of being unlovable, unworthy and of no value. Attempts to challenge or escape the norms of the local community illicit further abuse.

Service responses

Service response will also be variable in their impact on the adjustment to trauma, both in terms of the different types of services involved and the way in which service providers are conceptualising the response to trauma. Different responses to different perceived levels of madness, i.e. neuroses receive less disablist attitudes than psychosis because the latter is perceived as being outside the 'normal' range of experiences. Neuroses tend to be written off and considered a female condition whereas psychosis produces fear and rejection, 'othering', too different The interplay between psychosis and adjustment to trauma could be useful in challenging this.

In working with complex trauma as in Sally's case study, there is a need to 'deal with' the trauma and consider what trauma specific therapy may assist with the adjustment behaviours. There is a tendency for service provision to work around the trauma adjustment and deal with consequences of 'symptoms' e.g. self harm, alcohol/drug use, offending behaviour. The author's propose that viewing such as reporting psychotic phenomenon, self- harm, substance abuse as a spectrum of adjustments to complex trauma will enable practitioners to engage more effectively with clients. This raises question around the need for practitioners to be trained and supported in asking specific

questions about past experiences of trauma and abuse and responding appropriately to any material disclosed.

Wider societal responses

Research has demonstrated that bio-genetic causal beliefs are correlated with increased fear and prejudice (Read et al 2006), therefore the authors propose that a more psycho-social explanation for psychotic symptoms should defence against the more severe disabling responses from wider society if these were to be used within anti-stigma campaigns.

The social model of disability may be a useful starting in understanding the outer layers of the onion, but there are limitations. Firstly there is the notion of self- identity and how the client group view themselves. They may not see themselves as disabled. Secondly does the social model framework conceptualise this complex interplay between the outer layers of the model and the inner layers? By locating some of the causes of disability within the arrangements/organisation of social structures the SM begin to explain some of the experiences this client group has, e.g. repeated rejection by the services intended to provide support.

Morrison, A.P. et al (2003) propose that there is evidence to support all three of the following theories, that psychosis is caused by trauma, psychosis causes PTSD and 'psychosis and PTSD are on a spectrum of responses to traumatic events', clearly such a complex phenomenon requires a sophisticated framework for understanding, hence the development of the authors visual representations of the various layers and interplay between society, and self in trauma adjustment.

Conclusion/ Further Discussion

Despite the findings of Read *et al*'s 2005 literature review of large scale general populations studies on the links between childhood trauma, psychosis and schizophrenia revealing prevalence rates of a history of childhood abuse, in in and outpatient populations (at least half of which had diagnosis of psychosis), of 59/1% in men and 68.8% in women which led them to conclude that 'Symptoms considered indicative of psychosis and schizophrenia, particularly hallucinations, are at least as strongly related to childhood abuse and neglect as many other mental health problems' and that the relationship is a 'causal one, with dose effect', a recent survey of psychiatrists (Baillie, D et al, 2009) still found that most psychiatrists thought that biochemical and genetic factors are significant in the aetiology of both depression (70%) and schizophrenia (85%), whereas the role of 'childhood factors' were assessed as being more important in someone diagnosed with depression (65%) compared to only (20%) if the person is diagnosed with schizophrenia. Why this dominance of the role of genetic and biochemical explanations remain for schizophrenia in the face of contradictory findings is evidence of the continuing hegemony of the medical model of mental disorder.

Using the composite case study of Sally, the authors have been exploring the multi-faceted interplay between trauma and presenting behaviours such as psychosis. The case study explores issues of complex trauma, where the client has had multiple experiences of trauma over their lifespan. The range of mental health diagnosis in relation to symptom presentation could be reconceptualised as trauma adjustments. The trauma adjustments and interplay between society, community, family and self-have resulted in impairment for Sally. If her impairment continues to be conceptualised in terms of her presenting symptoms, the most recent, psychosis, what are the chances of recovery and adjustment?

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Which model of disability can include voice hearing experiences?

Bob Sapey

I'm coming to this debate as someone who has long argued that the social model of disability is the appropriate way to explain the disadvantages faced by disabled people and that it also provides a framework for understanding how best to organise and deliver disability services. However I have struggled to use the language of the social model of disability when communicating with people who have experienced mental distress as it can be perceived as offensive, stigmatising and irrelevant.

Using the social model of disability, in analysis or practice, is dependent on understanding the specific meaning attached to two key terms, impairment and disability. UPIAS set out to change the ways in which these terms were commonly used so as to emphasise their challenge to the idea that the economic and social disadvantage that disabled people experienced were the result of individual problems.

> ... it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.
>
> (UPIAS, 1976)

Several writers have argued that the social model of disability offers a useful way of exposing and understanding the way that society responds to and affects people experiencing mental distress. Julie Mulvany (2000) argues that health sociology would be advantaged by the overtly political aims of disability studies, but she doesn't challenge the construction of emotions as 'psychiatric disorder'. Helen Lester and Jonathan Tritter (2005) use the social model as a way of also understanding distress, but continue to accept terms such as mental illness. Liz Sayce (2000) acknowledges the range of ways in which distress may be constructed and argues that the social model of disability can help to counter the shame that may be felt by those experiencing a social response to their distress. Peter Beresford (2002) argues that the social model helps to shift the focus away from notions of individual tragedy onto the social contexts in which people experience distress, which he thinks is important in relation to human rights and independent living.

Clearly, mental health system survivors and disabled people share many objectives and over time the definition of impairment has been expanded by disability studies academics to encompass both learning disability and mental distress. However, as Anne Plumb (1994)has argued there are difficulties that arise from this. While people experiencing mental distress have fought for a de-medicalized understanding of their emotional responses to social experiences, the understanding of impairment within a social model of disability is a barrier to their inclusion in this model. In relation to voice hearing, the labelling of distress as impairment is central to the medical construction of emotions as illness, something which groups like the HVN are fighting.

Traditional psychiatry treats auditory hallucinations as the result and symptom of disease. Hallucinations are considered to be forms of perception in the absence of external stimuli, hence they are created internally. While mirages might be caused by dehydration and psychedelic experiences through taking LSD, the voices heard by people diagnosed with schizophrenia are supposed to be caused by chemical imbalances in their brains. The aim of pharmacological psychiatry is to stop the voices by using drugs that are intended to correct this abnormal brain state.

A social model of voice hearing[8] treats the experiences as real, rather than as hallucinatory. The voices might still be perceptions, but they are not without external stimuli. The main causes are considered to be life experiences, particularly trauma. The response of social psychiatry is to help people cope through understanding the meaning of the voices and through direct dialogue and negotiation with them.

The Hearing Voices Movement and its professional allies challenge the expertise of pharmacological psychiatry. While the HVN is also concerned about the social responses to voice hearers, their primary challenge concerns the construction of their emotions as symptoms of disease. This argument questions the medical credentials of psychiatry and offers an alternative explanation for the experience and an alternative therapeutic practice. Ron Coleman[9] has described the HVN as an emancipation movement for professionals as much as for voice hearers.

Marius Romme and Sandra Escher's research has shown that about 1 in 3 voice hearers find their experiences disturbing enough to seek professional help. Voice hearing can be extremely disturbing and may adversely affect people's participation in social and economic spheres of life. Stigma and discrimination along with constructions of dangerousness compound these problems. From a social model of disability perspective this could be described as impairment effects and disablement. However this is not a satisfactory way of accounting for the 2 in 3 voice hearers who have learned to cope and do not experience distress. Neither does it allow for a construction of voice hearing as emotion, rather than impairment.

Impairment and disability also have particular negative connotations in relation to mental distress in English law. Human rights legislation makes specific exceptions for people of 'unsound mind' and meeting the criteria for this has been left to psychiatry to determine. English law uses or has recently used terms such as mental impairment, mental illness and disability of the mind. All of these are used as part of the criteria for the removal of rights and for the use of compulsion – the language is neither neutral nor empowering for people experiencing distress such as voice hearing.

So is this an issue of language? Peter Beresford (2005) argues that others see people as mentally impaired and respond to them in discriminatory ways, so it is not necessary for people to self-identify as impaired. But I'm not sure this is enough as the term impairment has such strong meaning when applied to mental as opposed to physical. And despite his argument that people do not have to identify as impaired, the social model of disability retains the idea of impairment. Could one have a social model of disability without impairment?

One of the most significant developments in the social model of disability since it began was Carol Thomas's (1999) proposal for the inclusion of impairment effects and of the psycho-emotional effects of disablement. Setting aside the words for a moment, what this does is to argue for the inclusion of the kind of difficulties people may experience in being less able to participate due to distress. She also makes the case for recognising the emotional consequences of oppression. Are these developments any more inclusive?

Perhaps in this model it would be possible to substitute the word impairment for distress – distress effects? However, I am not sure that would work the other way so an inclusive model might have to talk about impairment or distress. When we start to stretch definitions in that sort of way it becomes difficult to sustain discussion as the language is becoming convoluted. And it raises the question of whether impairment is the best term in relation to physical disability? Is it inclusive of all chronic illness? Is it inclusive of deafness?

As well as the meaning and implications of the term impairment, the term disability is not without problem. While there is likely to be agreement in terms of the process of disablement as the

8   This term is used by Romme and Escher, see for example Romme, M. and Escher, S. (2000).
9   Madness Radio: *Living With Voices Ron Coleman*, 3.7.11.

negative impact of social attitudes and actions, disability is also widely used as an alternative for impairment. In this sense it has negative connotations and it is difficult for those outside of the politicised arena of UK disability movement to accept disabled as anything other than a negative label.

The term, person with disabilities, is used in many parts of the world as a way of putting the person first. In the UK the term, disabled person is preferred as it implies that disablement is something that happens to someone. This causes difficulties in communication of meaning which can result in people being offended. However, there is another issue when the language is extended to other groups, the problem of colonialism. Anne Plumb gives us the individual example of the person writing to *Coalition* in 1990 to express his wish to care about people who have had nervous breakdowns. She argues that there is something in this protective approach which shows a lack of knowledge for her history. If there is a value in having a common model for explaining the experience of disabled people and people experiencing mental distress, then there needs to be a common language rather than for one group to colonise the other.

The social model of disability is used to challenge explanations of disadvantage based on individual deficits. However, there might be agreement within disability politics that when it comes to impairment, genetic illnesses such as Huntingdon's Chorea and Cystic Fibrosis are the result of such deficits. However this cannot be the case in relation to mental distress where the individual deficit model is used to define its nature. Mary Boyle (2011) argues that this is one of the avoidance strategies of psychiatry, to dismiss the evidence for environmental and experiential causes of distress. In confronting that avoidance it would be difficult for someone who is hearing voices to use the language of impairment to describe that emotion or to use the idea of disablement to describe the power and control that psychiatry has over them.

The two points that I drew out of this in the symposium are:

1. Is this simply a UK problem in that in promoting a social model of disability we have changed to the meaning of our language in such a way as to exclude some people?
2. While the social model of disability challenges individualised explanations of disadvantage and these are commonly associated with the medicalisation of social and economic worlds, it remains essentially within a medical paradigm in terms of understanding the body. This may not be sufficient to act as a model that can explain the experiences of madness.

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Diagnosed victims, survivors or disabled women? Exploring pathology and the uses of self-identity at the intra- and inter-sections after disablist hate crime and rape

Susie Balderston

During research and advocacy work with disabled people after disablist hate crime (including rape), some of the debates which are relevant in examining, "Distress or disability?" have been particularly foregrounded. Disablist hate crimes, after all, are attacks perpetrated because of someone's identity, so how disabled people and Survivors are labelled and how we self-identify after attacks offers a potentially important example for disability studies and social work. The examples and constructions in this paper are gathered from user-led research over five years in the North East of England, with 428 surveys, focus groups with 220 disabled people who had experienced and survived violence, abuse and disablist hate crime (Roulstone, Thomas and Balderston, 2011) and an Action Learning Set of Survivors, disabled people and victim services (n=12), which made recommendations for policy and practice (Balderston and Roebuck, 2010). In these projects we stumbled across and confronted the labelling and pathologising from service-lands in health, criminal justice and social care services. In contrast, the participants also explored the rich possibilities of shaping self-identity collectively and the resisting of labels. This paper considers the data from these projects to assist us in understanding the interplay between disabled people, trauma, mental health service use, using a social model frame. These barriers will then be critiqued using feminist intra-sectional (cultural) and inter-sectional (structural) frames after Lykke and Crenshaw respectively, which may be most helpful in analysing the particular experiences at the intersection of disability, gender and violence, focussing on those barriers outlined from the research. In concluding, the paper will explore similarities, distinctions and diversities between disabled people and Survivor service user groups after hate crime, grounded from the questions raised in the studies and symposium.

Does the social model of disability offers a useful frame of analysis in relation to disablist hate crime?

Many participants described multiple barriers after hate crime. Attitudinal barriers may have compounded the harm of their experiences, with disabled people and psychiatric service Survivors often not being believed by statutory agencies, including the Police, doctors and local authority reporting services, resulting in many cases not being fully investigated or handed for Prosecution. When disabled victims did manage to have the perpetrator arrested, few were offered special measures to ensure equal and safe access to Court proceedings.

Participants in our study who tried to use Victim Support, either could not access their information or premises, found that victim support services often denied their Survivor status and inhibited collective action, or found the support to be ineffectual if they had experienced violent or sex crimes against them, which correlates with Rose et al's findings (1999). However, volunteer counselling through Victim Support still received £35 million in 2010, compared to £1.36 per victim of hate crime given for community interventions, despite an international evidence base questioning it's efficacy and showing that in circumstances it can even be damaging; this imbalance may disproportionately impact on people who need culturally competent and accessible services (for example, counselling in British Sign Language) where mainstream barriers exist. When victims are diverted to mainstream mental health services, further attitudinal barriers abound; experiences of hate crime or rape are invisible or ignored in assessment or treatment, despite participants regularly attributing the violent event as triggering their mental health service need.

This research does suggest that the barriers to access understood in social model terms, are significant for example with Deaf people (who do not identify as disabled people, but as a cultural group), disabled people, HIV positive men and women, assistance dog owners, psychiatric Survivors,

and other diverse groups who had physical and sexual violence perpetrated against them on the grounds of their identity (or perceived identity). It is here that the binaries of, "Distress or disability?" begin falter; people with accredited physical or sensory impairments may experience mental health service need and people with an experience of Surviving or using mental health services, or who have been given a psychiatric diagnosis label, may gain other physical impairments, not least becoming a disabled person or Survivor through the effects of violence.

Stigmatising labels?

So, if the categories of disabled people and Survivors are blurred and we share some barriers and have diverse characteristics, too, at different times, how do we choose to identify ourselves? 93% of our respondents in the surveys recognised themselves as being protected by the then legal definition of disability as having a substantial, long term impairment but only 87% considered themselves to be a disabled or Deaf person. Over 100 mental health service users and Survivors who had experienced violence also used the terms victim or S/survivor.   Only two mental health service users chose to give their diagnostic, accredited medical label. The most startling result in the context of this symposium is that in surveys from 428 respondents discussion group notes and transcripts which involved 222 disabled people in the North East of England, only once did the term, "Distress," arise. It was used by a service user discussing how disabling and inappropriate she had found the National Institute of Clinical Excellence guidance approach of categorising mental health service need as distress or anxiety, but failing to then include experience of crime (in her case a very violent rape) in the assessment process.

In experiencing physical and sexual violence, for which our participants were all targeted because of who they were or how they looked, a diverse group of people came together primarily in working through, resisting and adopting the identities of victim (which feminist analysis may find problematic) and Survivor. This included proud disabled people who adopt the social model, people with impairments who hide normalise themselves, people who reject political identity or accept medical categorisation, people who have been sectioned under the Mental Health Act, trans women who have been labelled as mentally ill and who have survived psychiatric system violence in order to achieve transition of their gender and people who have been labelled as having a variety of impairments, -istics and difficulties, or classed as, "Vulnerable," adults. Of course, actors in the disability movement do not all, over time or at all, identify as part of it, or adhere unerringly to the social model of disability, consistently and with a fixed identity.

I would apologise that the disability movement has sometimes itself generated the refusals of Survivors to work with it, as Butler explained about feminisms some decades ago (1990, p4). However we may choose fluid identities at different times which are useful to us when we come together as allies, sisters and supporters of each other's campaigns, with support offered through a shared acknowledgement that we are oppressed and discriminated against in different ways.

Do we experience trauma?

Similarly, as psychiatric manuals chose to understand, "Trauma," as initially being derived from, "An event outside the range of human experiences," (APA, 1987) then reactions to disablist hate crime which includes rape cannot be understood in these terms, as it appears from our study at least, as violent attack appears to be not uncommon or unusual in the lives of disabled people and Survivors. For example, 71% of disabled respondents had experienced violence, harassment, assault or abuse in the two years before the study (compared to only 24% of non-disabled people).   Other, national large scale surveys (which are often not accessible to disabled people) suggest the rate may may be 11% and the actual figure, perhaps somewhere between, is not yet convincingly demonstrated.   So, in acknowledging disablist hate crime is a regular occurrence, what might reasonably be the disabling effects of this on disabled people? The British Crime Survey gives some indications that the effects of crime may be 20% greater for disabled people who experience crime aggravated by their identity (Iganski, Nocon and Lagou, 2011), but it excludes data gathering from many people who

need accessible formats, are assessed as lacking capacity or residents of institutions, so how are we to really assess the impact?

Again, no participants or respondents in our studies have referred to anything expressly using the language which locates experience as, "Traumatic," apart from one example of a woman's victimisation at the hands of criminal justice and health services after the attack. Our research concurred with other research findings that disabled people and psychiatric system Survivors are often stigmatised and blamed as victims, in a way that people who are treated after trauma from natural disasters, for example, are not (Brown, 1995, p101). So, in using a political frame, grounded in social model understandings and Survivor experiences, it is illuminating to see how medical and theoretical concepts of, "Trauma" and "Distress" continue to disable us, even after we have existed through severe violence and rape.

It is therefore argued that collective, user-led approach to safe and ethical research producing grounded theory, may be important in terms of Oliver's disability research as part of the struggle for rights, when concerned with disablist hate crime. Disabling constructs, produced often by non-disabled researchers, asking other people in our lives (such as parents, service providers or medics) to discuss and frame our experiences of violence, without disabled people leading, collecting or analysing the data, is still disabling us today, even after almost twenty years of the movement and academy setting out the framework for emancipatory, ethical, disability studies research. These barriers between activists, victims, Survivors, disabled people and the academy are surprisingly pervasive and distressing to disabled people are still treated as subjects of research, long after Survivors set out the framework for working ethically in the field (Faulkner, 2004). Our research findings show that critical disability studies and post-modern analysis without disabled people or Survivors designing, curating and analysing the work, is not a new development, but can be experienced viscerally as a return to an individualistic, pathologising state of research before disability studies gave us space and agency to tell our own stories. In ignoring (or compounding) inequalities of resource, power and voice between social groups, researchers who play with analysing our discourses can disable us even further.

The significance of a gendered approach?

In addition, the 'problem of disablist hate crime' presents as heavily gendered, paralleling the attack, stigma and labelling against women mental health service users, all the way from the label of 'hysteria' to contemporary times (cf. Ussher, 1991, Showalter, 1987). International literature already evidences that disabled women, in particular, appear to be between two (Smith, 2008) four times (Martin, 2006) at risk of abuse and assault, compared to non-disabled women (including mental health service users) and more likely to be attacked than disabled men, so a gendered view on the subject is constructive.

Presently, there are only a handful of studies which Begum has clearly outlined as considering the, "Simultaneous oppression," of disabled women (Campbell and Oliver, 1996, p127), so disabled people and S/survivors groups could be welcomed to add to the literature in the area. As we move to be more visible in community settings, social arrangements that isolate us (where we do not have peer support, for example CILs, circles of support or Clubhouse models) and where we are not linked in to local communities of non-disabled people, for example, through Circles of Support, we can be at risk of hate crime or rape, because of the barriers created by individualistic models which have new barriers in them. Whilst we will always be at more risk of violence and abuse in institutions than in the community, independent living and so research about disabled people's lives in that context, could do well to learn from feminist, intersectional approaches. McCall (2005, p1772) explains that this is necessary to analyse, 'Changing configurations of inequality along multiple and conflicting dimensions,' and is ideally suited to shifting identity in relation to disabled women who experience violence, as violence, gender and disablism are not simply additive in the context of hate crime.

This approach has been particularly illuminated by participants in the North East research, who have seen themselves as victims, Survivors, campaigners, disabled women and latterly seeking to identify as, "Happy women," (Taylor and Pugh, 2010) at different places and times in their collective and individual journeys after disablist hate crime and rape. The invisibility of these self-identities in relation to criminal justice and mental health provision still persist, with only victim and diagnostic labels being recognised in statutory services. Again, this imposition of pathologising labels was experienced across the many diverse groups who may be seen from the outside at least, as part of the diverse disability movements in the UK.

We are still to test the usefulness of psycho-emotional disablism as a construct in relation to disablist hate crime and Survivor experiences, in 2011. Conversations about the usefulness of psycho-emotional disablism with participants are still to be undertaken, but the symposium was helpful in discussing some problems with the risk of 'well-being' in the Thomas definition as being misinterpreted and appropriated, in the way we have seen the Survivor notion of recovery seized by services in the last decade. It is a useful parallel here in wondering whether 'outsider' (e.g. white, secular, male) researchers would be seen as ethical if they chose to voyeuristically question victims or Survivors of identity groups about the traumatic effects of violence on their self-worth, who, like disabled people, experienced the Holocaust, or who had experienced racist rape at the hands of the Ku Klux Klan? So, more discussions about the safety of this model to ensure participants are not re-traumatised by discussing their experiences and the training of insider researchers to undertake this research in culturally competent and emancipatory ways, so that subjects are not pathologised or voyeuristically studied are needed before it is used. Some participants have asserted that for them, a reaction after a violent disablist hate attack or sexual assault is entirely understandable and human, without the victim needing to have added a pathologising, diagnostic label. There are significant ethical issues of exploring impacts after violence are thorny and user-led design, using Faulkner's ethical framework for Survivor research (2004) is essential here; these Survivor frameworks are areas from which disability studies researchers can learn much.

Perhaps, then, more useful activities for non-disabled researchers interested in disablist hate crime and violence, than concerning ourselves with whether victims might be experiencing psycho-emotional disablism is the "Researching up," of the non-disabled professional shame and disabling stigma (Keith, 1996), in the way that Goodley has suggested the psycho-pathology of non-disabled people as a useful frame. In addition, the necessary inclusion of Survivor researchers in the debate, who do not purport to speak for, or interpret the views or experiences of others, but who may be suitably someway through their own experiences and who have a collective power, are predicated. Without it, constructions such as those seen in the research by Hassouneh-Phillips & McNeff (2005) are risked; for them, the problem of violence against disabled women is linked worryingly to low self-esteem and poor body image in the women themselves; the risk is that poorly employed in terms of trauma, psycho-emotional disablism may locate the problem right back in blaming the victim and fuel the industry that surrounds them.

In these outcomes and disabling constructions of pity, sensationalism and 'shock' invoked in discussing violence against disabled people, it is too easy to see post-structuralism fall well short of Laclau and Mouffe's (2001) politico-emancipatory aims. In contesting the rightful voices in a field, perhaps Survivor research has been more effective than disability studies, even at its most emancipatory, could manage.

A false choice between, "Distress OR disability?"
The differences and contested identities and labels so succinctly outlined by Thomas and Plumb, are both commensurate with accepted social movement theory (also recognisable from feminisms); Della Porta and Diani demonstrate compellingly, for example, that groups do not have to be homogenising or impose identities to be part of a broad struggle for rights. They see identity in social movements as being nurtured in small groups (2006, p96) but argue that it is solidarity

between these groups as being important to maintain, revive and effect collective action over time, as many disabled activists and Survivors may seek to do. In the terms of this symposium, disabled people and Survivors have been institutionalised and subordinated in different places; the labour market, criminal justice system, psychiatric or medical systems, segregation from education, for example, but share a struggle for rights in the future. So, as allies against oppressions, disabled people and Survivors are using our own chosen campaigns, strategies, strength and focus on our own struggles as part of a wider end.   Benford and Hunt (1992) recognise the vibrant arguments within social movements as, "Competition to affect audiences interpretations of power relations in a variety of domains," but it is in tackling shared problems, such as the lack of accessible and culturally competent responses after violent and sexual disablist hate crimes against us, in which we can share our campaigns, skills and voices. It remains for the academy to demonstrate that it can ethically engage in this debate around disablist hate crime and violence, without further pathologising subjects and groups. This symposium, in which Universities in the North West invested resources and brought together disabled people, Survivors, academics and practitioners in an accessible way, to honestly and safely discuss their problems and common ground is an excellent model for future collaborations and trust-building between disparate groups. The next step may be a protocol for mainstream research involving (or discussing) disabled people (particularly where violence is concerned), to ensure that ethical boundaries are not breached.   Further, the representation of Survivors, service users and disabled people on Ethics Committees and grant bodies, in the way that has been piloted by some Royal Colleges, Involve and the National Institute of Health Research, could be extended to provide even greater righting of historic (and contemporary) wrongs in disability research. The banners shared by abuse Survivors and the disability movement, "Nothing about us, without us," offers an easy test by which academic integrity can be judged, so that disabled people and Survivors may not be much longer the playthings of pluralistic, and perhaps non-disabled, researchers.

In summary

User-led research in the North East of England demonstrates convincingly that for us, the barriers experienced after hate crime can be coherently understood using the social model of disability and a gendered approach.   We have yet to discover whether participants are compelled to conceptualise, explain or recognise their own experiences in terms of psycho-emotional disablism.

But we can say that in considering the use of language by disabled people and Survivors in relation to their experience of violence and rape, data demonstrates that our respondents adopt no simple binaries imposed on us from ungrounded and non-disabled academics or service-lands which take no account of the inequalities or barriers we experience; we are not simply physically disabled or mentally ill, accredited with having either physical or mental impairments; we may be at once disabled people, victims and Survivors, all or none of those things, depending on the barriers we are facing and the space we are afforded in which we can take our own agency and the context in which we find ourselves.

Our tentative steps in joint project working have demonstrated that in some areas, for some struggles, over fifteen years on from Plumb's important discussion paper, many user-led organisations in the disability and Survivor movements, borne from various experiential discriminations, can seek to avoid dominating each other intellectually, financially or politically and work together for shared ends, whilst celebrating our diverse skills and identities. It could be argued, however, that we are about to be allies in another struggle, against hegemonic threats from perpetrators of hate crime, to post-structuralists, gate-keepers, individualistic models and charitable organisations that profess to speak for and about us, without us.

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Live and let die: Global mental health and critical disability studies

China Mills

Burdens, epidemics and crisis

While the title of this publication 'Distress or Disability', and the symposium it arises from, alludes to debates in the UK over whether mental distress can be usefully conceptualised using the social model of disability; on a global scale, the World Health Organization (WHO) already conceptualises mental distress as a disability, as 'mental illness'. In the Global Burden of Disease Report (2005) the contribution of mental health problems to global disease were measured using the 'disability-adjusted life-year' (DALY - the sum of years lost to early death and years 'lost' due to disability); finding that about '14% of the global burden of disease has been attributed to neuropsychiatric disorders' due to their 'chronically disabling nature' (Prince *et al.*, 2007).

The conceptualization of mental health problems as a disability, and more specifically as a non-communicable disease, and their measurement using DALYs has been key to the growing area of global mental health advocacy. For while mental health problems make a relatively small contribution to mortality in comparison for example to heart disease, they contribute highly to years 'lost' to disability (within an economic framework). This calculated global 'burden' of mental health problems can then be compared to the burden of other diseases, for example, while neuropsychiatric disorders account for 13% of DALYs; HIV/AIDS accounts for 6%; and Cardiovascular disease for 10% (WHO, 2003). However despite their higher 'burden', with 'four of the six leading causes of years lived with disability … due to neuropsychiatric disorders (depression, alcohol-use disorders, schizophrenia and bipolar disorder)' (*ibid*), neuro-psychiatric disorders do not have high prominence on the global health agenda, and 'in most parts of the world, mental health and mental disorders are not accorded anywhere the same importance as physical health' (*ibid*). This low profile is reflected in the fact that '[o]ne-third of the world's population – 2 billion people – lives in countries that spend less than 1% of their health budgets on mental health'; 40% of countries do not have a mental health policy; and one quarter of all countries do not provide disability benefits to people with mental health problems (*ibid*:39).

Framing mental health problems within a register of disability enables those who call for global mental health advocacy, such as the Movement for Global Mental Health, to identify 'priority disorders' (such as depression, schizophrenia and dementia), 'on the basis that they represent a high burden (in terms of mortality, morbidity, and disability), cause large economic costs, or are associated with violations of human rights' (Patel *et al*., 2008). Global mental health advocates can then mobilise the call for Government's to take 'mental illness' more seriously through increasing public spending on mental health and 'to scale up the coverage of services for mental disorders in all countries, but especially in low-income and middle-income countries' (Lancet *Global Mental Health Group,* 2007), where ' 75% of people do not get the mental health services they need' (WHO, 2008).

It is worth noting a few things in this call to respond to suffering through the lens of psychiatry, in low- and middle-income countries (what we might call the global South). A key strategy in using the DALY to measure the 'burden' of mental health problems has been to group together neurological, mental and substance-use disorders into one disability category, as 'neuropsychiatric disorders'.[10] The Movement for Global Mental Health also urges HIV/AIDS activism to be used as a model for global mental health advocacy (Patel *et al*., 2006). Both these strategies imply that mental health problems are 'illnesses', and that 'mental illnesses' have underlying biological components comparable to those for dementia and epilepsy, thus invoking parallels between access to psychiatric medications and to medication for epilepsy, and anti-retrovirals for HIV/AIDS. This

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[10] It is worth noting that the WHO refer to mental health problems as 'neuropsychiatric disorders', thus immediately framing these experiences within a bio-psychiatric register.

constructs mental illness as 'an illness like any other'. It is on this basis that the Movement for Global Mental Health then calls for a move beyond the 'scientific evidence base' of particular treatments (which are taken as well-established) (*ibid*), and pushes the 'moral case'; 'that it is unethical to deny effective, acceptable, and affordable treatment to millions of persons suffering from treatable disorders' (Patel, 2006).

However there are some problems in making the argument above, particularly because the evidence for the organic basis of mental health problems, such as schizophrenia, is not as considerable as certain claims suggest (Moncrieff, 2009; Chua and McKenna (1995). This is further complicated by the fact that while research that uses placebos, for example in HIV/AIDS, has been widely criticized because it denies participants the best currently available treatment (Shah, 2006); in many trials for depression, drug-placebo differences have been found to be not statistically significant.11 This is not the case for the use of placebos in HIV/AIDS research.

A further complexity in the call for global mental health is that findings from international comparative studies by the World Health Organisation, and the World Mental Health Survey, suggest that low- and middle-income countries actually have better long-term outcomes for mental health problems (such as schizophrenia) (WHO, 1973); and despite so few people in low income countries receiving treatment, prevalence of mental illness is much lower than in high income countries.[12] Findings from within high-income countries also point to better outcomes for people with a diagnosis of schizophrenia who are not medicated, and worse outcomes for those who are (Rappaport, 1978). In the UK, where access to medication is higher, David Healy *et al* (2001) point out that since the development of modern psychotropic drugs; we 'now compulsorily detain three times more patients… [and] admit fifteen times more patients'. Robert Whitaker (2010) shows that since the advent of psychotropic drugs the number of people claiming social security for disability increases each year in America, with 50% of children registered as disabled having mental health problems. A further layer of complexity in the relation between mental illness and impairment is the wide evidence that long term use of psychiatric medications may lead to iatrogenic impairment, for example tardive dyskinesia, motor tics and headaches (Gardos and Cole, 1978) and in trials of anti-depressants with children the drugs were found to increase suicidality (Healy, 2006). However rather than calling into question the long-term efficacy of medication, iatrogenic impairments are often framed by psychiatry as 'symptoms' of an underlying disorder, just as increased suicide is read as being due to the 'mental illness' Whitaker, 2010). All this begs the question of what is global mental health 'scaling up'? This is a problematisation of the push to conceptualise mental illness as an 'illness like any other'; and the administering of anti-psychotics as parallel to administering anti-epileptic medication (WHO, 2008).

The above research also problematises the WHO's conceptualisation of distress through the lens of disability, the push to make distress understandable within a social model framework. The Union of the Physically Impaired Against Segregation (UPIAS) defined impairment as 'lacking part of or all of a limb, or having a defective limb organism or mechanism of the body' (cited in Oliver, 1990). However the research discussed above points to little evidence of an organic base or defective mechanism of the body linked to mental health problems, raising the uncomfortable question of what is the 'impairment' in mental health problems as conceptualised through the social model of disability? And perhaps more central to this paper, what function does conceptualising mental illness as impairment serve? Understanding mental distress through a social model of disability lens, may serve more than one function, linking explanations of mental health problems to particular political rationales. This links to concerns raised at the symposium for which this paper was written, about the social model of disability's assumption of 'impairment', and thus it's potential to let the medical

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[11] See Irving Kirsch's book *The Emperor's new drugs: Exploding the antidepressant myth*.
12 World Mental Health Survey http://www.hcp.med.harvard.edu/wmh/ (Accessed 29.9.11).

model, and biopsychiatry, in through the 'back door'.[13] Taking this further, Ann Plumb asks (in chapter 3 of this book) whether something fundamental to the survivor movement has been lost in the framing of distress as disability, particularly in the bending of the survivor demands to fit the disability discrimination agenda, underpinned by the social model of disability, and with this the opening up of the potential for 'unsound mind' to creep into global disability discourse. This points to the need to disentangle impairment from the social conditions that give rise to it, particularly as the survivor movement stresses the importance of reading distress as both personally and politically meaningful (with experiences such as hearing voices often related to trauma).[14]

It is here that critical disability studies (see Goodley, in this publication) might be a useful resource in thinking beyond the binary positions of the social model of disability and to deconstruct impairment as neither a 'presocial nor pre-cultural biological substrate' (Thomas, 1999). This would then enable a reading of what political rationales are being served by constructing mental distress as biochemical impairment, particularly as health emerges as a global marketplace. The push to conceptualise mental distress as an illness, like any other, is according to Read (2005) 'promulgated by biological psychiatry and the pharmaceutical industry, [and] is not supported by research'. This calls for recognition of the pharmaceutical industry and psychiatry's complicity and power in framing what we can recognise as normal, abnormal or impaired. As well as their role in responding to and mediating distress in countries of the global South – through an underlying rationale of biomedical psychiatry; based on the assumption that drug intervention will restore the subject to a 'normal' condition, what Lakoff (2005) terms 'pharmaceutical reason'.

A 'mental health literate society'

Mental health awareness and education campaigns working to improve 'mental health literacy' aim to teach people in lower-income countries how to recognise and respond to mental health problems, with the aim of creating a 'mental health literate society' (Jorm, 2000), where 'mental health for all is a reality'(Patel *et al.*, 2011). However this mediation is interweaved with particular understandings of what it means to be human, that may depoliticise distress and delimit alternative counter hegemonic explanations and responses (from within the global South and North).The globalisation of biopsychiatry may work to discredit and make invisible traditional or alternative ways of knowing distress globally. This may be a cause for concern because research suggests that pluralism in understandings of and approaches to mental distress in the global South may account for the better outcomes for people with a schizophrenia label, in the so-called 'developing' countries of the WHO studies (Halliburton, 2004).

Bio-psychiatry is also underwritten by specific understandings and prescriptions of what counts as a person, potentially 'presenting as definitive the contemporary Western way of being a person' (Summerfield, 2008). Through a post-colonial lens, this could be read as an Orientalist project, 'a way of ... coming to terms with the orient in terms of occidental categories' (Chakrabarti and Dhar, 2010). That is, 'coming to terms' with lower and middle-income countries in terms of bio-medical and psychiatric categories. Global mental health discourse may thus work to transform lower-income countries into an image of the 'west', 'a reformed, recognizable Other, as a subject of difference that is almost the same, but not quite' Bhabha, 1994) – a lacking underside, lacking in psychiatric knowledge about mental illness. Re-reading bio-psychiatry as a colonial discourse, as a means of colonial subject formation, may be useful here in charting how 'mentally ill' subjects are interpellated and brought into being, marking a shift in human ontology that enables the biomedical reshaping of global citizenship (Rose, 2007); what Ashis Nandy calls the more covert colonization of

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[13] This concern was raised by Helen Spandler, in her introduction to the symposium, on the 15th of November 2011, at Lancaster University.

[14] See the work of the Hearing Voices Network www.hearing-voices.org; and Herman, Judith. Lewis. (1997). Trauma and recovery: The aftermath of violence from domestic abuse to political terror. Basic Books.

minds.[15] This may be problematic because while Gruzinski (cited in Rahnema and Bawtree, 1997) points out that colonization rarely destroys all creativity and resistance, 'it does succeed more than often in weaving indissoluble ties between indigenous cultures and the imported ones'. Here this may mean ties to medication that are biologically hard to break.

In this space, mediated through bio-psychiatric frameworks of recognition, distress is framed as 'mental illness', and 'mental health literacy' is taken to mean demanding access to medications. It seems then that conceptualizing and responding to distress globally through a bio-psychiatric register, the governing of mentality from a distance, may serve as a profitable business for the pharmaceutical industry, and psychiatry. Indeed, while the WHO conceptualise mental health problems through an economic discourse, as 'burden'; for the pharmaceutical industry, low-income countries such as India, 'with a population of over a billion is a largely untapped market',[16] a 'new promised land for drugmakers', as 'the industry's future now lies in the developing world'.[17]

An Illness like no other...?

However alternative frameworks from user/survivor literature, critical psychology and critical disability studies, enact a different reading of mental health problems as distress, not illness. Alongside the strong push to see mental illness as 'an illness like any other', it is possible to read another story that forces questions of whether some illnesses are in fact more 'real' than others, and further, why does having a physical impairment accord increased status to a particular experience or disability? It may be that mental illness is an illness like *no* other, or indeed better not conceptualized as an illness at all. This revisits arguments from the early days of anti-psychiatry; Thomas Szasz's (1972) assertions that mental health problems should be read not as illness, but as 'problems in living'; as sane reactions to an insane, unequal society.

In fact, within global mental health advocacy the exact opposite move is being made; to frame mental distress as 'illness', set firmly within a public, global health agenda. For example, within WHO literature distress is conceptualsied as 'neuro-psychiatric disorders', such as schizophrenia, which are described as chronic and very disabling (Patel *et al.*, 2007) and the Movement for Global Mental Health advocates 'to ensure the inclusion of mental health on the global public-health policy agenda, and the effective integration of mental-health care into every level of general health care' (Patel *et al.*, 2008). Thus despite WHO studies on the social determinants of mental illness, within global mental health it seems that the individual (impaired) brain remains the key site for intervention and transformation, often through medications. This, as Parker (1997) notes, 'constructs a place for people to experience their economic distress as a *psychological* problem and to look into themselves as if *they* were the cause of social ills'.

Perhaps nowhere is this more apparent than in analyses of farmer suicides in low-income countries, where there are estimates of 300,000 deaths due to self-poisoning with pesticides a year, in the Asia-Pacific region alone' (Patel *et al.*, 2007). While the economic and agricultural reforms, often introduced as part of Structural Adjustment policies by the World Bank and International Monetary Fund, that led to these suicides, are mentioned in some global mental health analysis, the very analysis of these suicides within a mental health framework, and thus any suggestions for reducing them, tend to centre on the 'effectiveness of reduction of access to pesticides, or improvement of medical care for pesticide poisoning in low-income or middle-income countries', and on improvement of treatment for depression and access to anti-depressants (*ibid*). Thus while analysis centres on the economic costs and burdens of mental illness, the potential economic causes of mental distress are often overlooked. The Movement for Global Mental Health also goes on to call

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[15] See Nandy, Ashis. (1997) The Intimate Enemy: Loss and Recovery of Self Under Colonialism. Oxford University Press, Oxford.
[16] Indian Pharma Industry SWOT Analysis http://www.scribd.com/doc/25040115/Indian-Pharma-Industry-SWOT (Accessed 14th June, 2011).
[17] (2008) 'Big drugmakers' love affair with America is coming to an end'. Pharmaceuticals, Nov 13th.

upon agencies such as the World Bank to increase funding into mental health interventions in low-income countries (Lancet Mental Health Group, 2007). However what are the ethics of making this call when it is reforms by the World Bank that may cause distress in the first place? It seems possible to trace a double movement here, whereby the distress caused by neoliberal reforms and inequality is mediated through a bio-psychiatric lens as 'illness', opening up interventions that are individual and often pharmaceutical, and that are thus part of the same neoliberal rationality as that which may have caused distress initially.

Distress at a Distance

Reading mental health problems as distress, not illness, as a 'nascent political text' (Butler cited in McRobbie, 2009) as ways of coping with and resisting social inequality and trauma, has historically marked a radical move by the psychiatric survivor movement against bio-psychiatry, and raises important ethical questions around what governs our global affective responses to distress. While critiques of psychiatry in high-income countries often centre around excess; for example in the frequent over-prescription of psychiatric drugs to children (Fowler, 2010), in countries of the global South millions of children die each year from lack of access to basic life-saving medications (UNICEF, 2008). This 'global letting die' (Rose, 2008) forces us to confront the frameworks of recognition that shape whose lives are worth living on a global scale, what counts as distress, and how that distress is mediated. What does the mediation of that distress within a disability register make possible, and what psycho-political demands might it foreclose? For example, in India the inclusion of persons with mental health problems within the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has been widely promoted by survivor and radical mental health organisations (such as Bapu Trust, in Pune).[18] Can and should we make an argument for taking mental health seriously within national and international policy, without medicalising it? A project of critical global disability studies would need to grapple with questions of how we can conceptualise the urgency of some situations of oppression, while resisting the inevitable hierarchies of comparison between low- and high-income countries, and between physical diseases, impairments and mental health problems without privileging one category or collapsing all into one. This project calls for an exploration of what frameworks we might employ to respond ethically to distress or impairment within low-income countries, without transposing bio-psychiatric and western knowledge systems, and of grappling with the project of taking mental health seriously globally and responding ethically, while retaining an understanding of the complexity and politicisation of distress.

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[18] See Bapu Trust website; http://www.bapucamhindia.org/

part three

Symposium Papers – Day Two

Is disability theory ready to engage with the politics of mental health?

Dan Goodley

Introduction

In this brief paper I want to explore a number of theoretical developments in critical disability studies. We know from the work of activist-writers such as Peter Beresford, Anne Wilson and others that the politics of disability and mental health system survivors have, at times, failed to connect. One reason for this disconnect is the failure of disability theory to adequately conceptualise the experience, phenomenon and constitution of mental health in critical and politicized ways. Consequently, activists and researchers in the area of critical mental health have felt marginalised by disability theory. This conference in Lancaster is obviously a welcome opportunity to reconnect the two fields and key to this exercise is the question of theory. This paper is very much a work in progress and I am looking forward to learning lots from the conference. In this paper I want to ask: are theoretical developments in critical disability studies ready to engage critically and collegially with the politics of mental health? I will aim to answer this question with reference to a number of established and emerging theoretical approaches in critical disability studies. This review draws, in part, upon an overview of theoretical approaches developed by Goodley and Runswick Cole (in press).

Materialism

In British disability studies *materialist* theories of disablement acknowledged the reality of impairment but shifted the attention away from the body (impairment) to society (disablement), particularly the structural and historical conditions of disabled people's marginalization (Oliver, 1990; Barnes, 1998; Gleeson, 1999). The ensuing framework of analysis – the social model of disability – emphasized analyses of the socioeconomic causes of oppression in sharp contrast to the impairment-obsessed focus of dominant disability discourses associated with medicalisation, psychologisation and rehabilitation. The body and impairment appeared to remain on the outskirts of disability theory and this prompting some scholars and activists to reinsert bodily concerns back into the social model discourse (French, 1993; Crow, 1996; Shakespeare, 2000). They argued, respectively, that the harsh realities of tiredness, the limiting consequences for social interaction and debilitating experiences associated with some impairments have often become obscured by the structuralist focus of the social model. A materialist perspective can clearly be drawn upon in an analysis of the politics of mental health to highlight disabling barriers that marginalise people with impairments. A social model addresses material barriers in fruitful ways. For example, the lack of flexible employment laws and policies – to accommodate for examples fluctuating impairment – need to be challenged. The standardisation of curriculum in schools and preferred forms of pedagogy are under-girded by a model of the ideal learner who is self-contained, entrepreneurial, able and willing. Materialists seek changes to education that include all learners and all forms of learning style. The place of impairment in social model thinking is, perhaps, more problematic for those engaged in the politics of mental health. While much has been written about the relative place of impairment in social model theory it is fair to say that the original definition of impairment offered by UPIAS (1976: 3-4) still dominates our thinking:

> Impairment - lacking part of or all of a limb, or having a defective limb organism or mechanism of the body.

> Disability - the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account of people who have physical impairments and thus excludes them from mainstream social activities.

As numerous observers that pointed out including Shelley Tremain, Carol Thomas and others, this definition of impairment individualises impairment: placing it firmly in the body and or mind. Such a

definition is clearly at odds with those critical mental health theorists and activists who aim to deindividualise notions of mental health. Indeed, as Parker (2008) has been key to demonstrate, the psychologisation of everyday life supports the taken for granted idea that mental health is an individual's pathology. The survivor literature, for example in the work of Sayce (2000), has very carefully and convincingly demonstrated the ways in which services, institutions and practitioners of the psy-complex risk maltreating and abusing service users through unproblematically assuming that mental health 'problems' or those only of the service user. It would, therefore, seem important for critical disability studies to think more carefully about we deploy particularly assumptions around impairment.

Realism

One of the more popular theoretical developments around the place of body and mind in disability studies, in recent years, has been made by *realist* disability theorists (Shakespeare and Watson, 2001; Shakespeare, 2006; Siebers, 2006). They argued that separating the body and culture – impairment and disability – ignores the realities of the body and the mind. The argument goes along the following lines. There are real bodies that exist materially untouched by culture as extra or pre-discursive phenomena. Impairment is a key reality of the disability experience. For some it is a predicament, for others unimportant but, for all, impairment is a manifestation of biological limitation (Shakespeare, 2006: 40). This realist conception of impairment has contributed to the drafting of universal definitions of disability such as *International Classification of Functioning, Disability and Health (ICFDH-2)* or *the ICF model,* where disability is an umbrella term for impairment, activity limitations, and participation restriction, and forms part of a broader classification scheme covering three domains: body functioning and structures, activities and participation, and environmental factors. Moreover, a realist approach fits well with a Nordic relational model of disability which approaches the study of disability with three main assumptions: (i) disability is a person-environment mis/match; (ii) disability is situational or contextual and (iii) disability is relative (Tøssebro 2002, 2004). For Campbell (2009: 95) a relational model understands disability as a phenomenon emerging out of interactivity between real impairments and disabling modes of socio-economic organization. Realists have encouraged discussion about the biological realities of 'non-normative bodies' (Shildrick, 2009) in ways often in opposition to social modellists. Nevertheless, by locating the body and mind in the biological register, then the non-normative body or mind is in danger of being theorised and understood through orientations that are commonly aligned with such a register; such as medicalisation, psychology, therapy and rehabilitation (Koch, 2008). While I welcome the contribution of writers such as Shakespeare to take seriously the issue of impairment – I think he has pushed researchers to up their game theoretically - this raises the question of what kinds of theories are helpful particularly to those interested in making critical and politicized interventions into arenas such as therapy. For those working from a critical mental health perspective, the idea that mental health is a biological reality is hugely problematic; particularly when we know that disciplines such as psychology have constituted and created the very phenomena that they purport to objectively measure. The Hearing Voices network, for example, has very clearly troubled psychology's relationship with mental health and have demanded psychologists to think again about how they conceptualise notions such as 'distress' and 'recovery'. The same demands should be made of critical disability studies.

Phenomenology

I would like to suggest that a more sustained social theoretical analysis of the body, mind and society has been provided by *phenomenologists*, whose ideas have been well represented in analyses of the dilemmas and possibilities of embodiment (Paterson and Hughes, 1999; Hughes and Paterson, 1997; 2000; Hughes, 2000, 2002a, 2002b, 2004; Michalko, 2002; Titchkosky 2003, 2008; Overboe, 2007). Phenomenologists attend to the capacities of the body to be a source of self and society. As Goodley (2011a: xx) has argued, a 'carnal sociology' has emerged, drawing on the work of such people as Merleau-Ponty (1962), theorising the body as *the* place where self and society interact (Shilling,

2005). Embodiment refers to how the body operates in the world at the intersections of the corporeal and institutional (Sherry, 2006). Comportment, for example, reflects conventions. Ability is a response to environment demands. Illness is a narrative written onto and lived with through recourse to a whole host of powerful narratives such as medicine and self-help. Bodies are sites for subjectivity and consciousness, our active vehicles for being in the world. Practical engagements with our surroundings inform the intentionality of the body. Senses provide thickness of meaning that then constitute the world around us. We open our selves and bodies onto – and by doing so – create environments (Merleau-Ponty, 1962). The experience of disability and impairment is conceptualized through reference to the social self and its production of the life world (Hodge, 2006), where the cultural constructions of disability and impairment are played out within and through the body. These accounts, then, allow us to consider the ways in which impaired bodies and minds are constituted through and with the relationships between the body and the environment. Phenomenology would appear to be a useful site in which critical disability studies and critical mental health researchers could meet to share ideas. The notion of being-in-the-world helpfully recognizes the ways in which the self and society; body and culture and intimately linked together. The work of Rod Michalko, for example, in his phenomenological studies of blindness say as much about the psychological and cultural constitution of blindness as they do about the 'sighted normative standards' of his and our everyday life. Similar explorations can be made into mental health and disability.

Psychoanalysis

Social psychoanalytic interventions into disability studies have had less impact on debates than other camps but their significance is starting to be felt (see Goodley, 2011b for an overview). This perspective uncovers societal, political and cultural knowledge/practices that impact upon the development of the un/conscious and the psyche. Marks (1999a, 1999b, 2002) has provided the most sustained analysis, suggesting that critical disability studies and social psychoanalysis are distinct though overlapping perspectives. First, each demand changes to psychic and environmental structures rather than just attitudes. Second, disability studies and social psychoanalysis reject medicalisation in favour of more relational encounters. Third, each reject unitary, rational, fixed and stable conceptions of the individual and consider categories such as in/sane, un/healthy and dis/abled as cultural continua that raise questions about human worth. Fourth, both psychoanalysis and disability studies have attended to the ways in which the self is made in relationships with others. This feeds directly into disability studies work that has long acknowledged how the disabled self has been consistently devalued by non-disabled others (see for example Hunt, 1966). One of the key tasks of psychoanalysis is to map how bodies and bits of bodies are positioned in relation to one another (Parker, n.d.). The contribution of social psychoanalytic disability studies to critical mental health is, I think, highly questionable not least because of the historical abuses of psychoanalysis to survivors of mental health systems. Many activists would see psychoanalysis as part of the problem of professional treatments. For this reason alone, as Kathy Boxall reminded me, why would an activist want to turn to the tools of the oppressor in disability theory? I accept this point but would also want to recognize the ways in which psychoanalysis can be used to identify, explain and challenge the 'psychopathologie' of the 'non-disabled'. If we accept that psychoanalytic ideas are all around us and are used in everyday parlance to shape how we understand our selves and others (Parker, 1997) then perhaps it makes sense to deploy these ideas to make sense of the various ways in which non-disabled society disavows disability. I am specifically interested here in non-disabled people's verbal or other responses to disability collected and shared by disabled people and others close to them. I want to make it crystal clear that I believe that not *all* non-disabled people engage the same responses to disability, that many non-disabled people are allies, friends, supporters and parents of disabled people and that we are all marked by differences associated with class, gender, age, sexuality, ethnicity, etc. However, I do want to expose and challenge some of the common reactions of non-disabled society to disability. This project could be extended across disability studies and critical mental health.

Postconventionalism

The final theoretical development is, for me, one of the most exciting and potentially the most receptive approach to a synthesis of critical disability studies and critical mental health. *Postconventionalist* theories, a term coined by Shildrick (2009), aim to reframe the disabled bodies/minds along the lines of capacity, potential, interconnection and possibility (Bayliss, 2006; Gibson, 2006; Goodley, 2007; Goodley and Roet, 2008; Hickey-Moody, 2009; Overboe, 2007; Roets, 2008; Shildrick, 2004, 2007, 2009). These theorists embrace poststructuralist and posthumanist orientations including the work of writers such as Haraway (1991) and Deleuze and Guattari (1987). A postconventionalist position is captured well by Haraway (1991) who describes social theory as providing subtle understandings of emerging pleasures, experiences and power with serious potential for changing the rules of game. What people are experiencing, she argues, is not transparently clear, and we lack subtle connections for collectively building effective theories of experience. This is particularly the case when bodies or minds challenge normative standards of embodiment. For Shildrick (1999) many theoretical conceptions of the body/mind assume a normative, seemingly biologically given, standard morthopology, integrated and fully functioning body as an implicit standard. The consequence for non-normative bodies is clear; they are marked as the antithesis of the standard:

> Against an ideal of bodily perfection that relies on the singular, the unified and the replicable, monstrosity, in the form of either excess, lack or displacement, offers a gross insult (Shildrick, 1999: 80).

Postconventionalists borrow then from phenomenological, poststructuralist and, to some extent, psychoanalytic theories to dispute the 'giveness' or 'already there' of any body. The body is, for Braidotti (2003: 44), neither a biological nor sociological category, but an interface, a threshold, a field of intersecting material and symbolic forces; a surface where multiple codes (sex, class, age, race, etc.) are inscribed. The normative body is understood as being fashioned and materialised through cultural, political and social conditions ranging from surgery to self-help. The non-normative or monstrous body – a body that appears as an object of fear and curiosity – is considered therefore as an opportunity to think through values, ethics and politics that congregate around particular bodies. In this sense any intimate bodily function is also a function of a body within given standards of embodiment whilst also, potentially, a moment of disruption and reflection on what counts as a valued body. Through these reflections non-normative bodies are recast as unique embodied entities through which we can consider how bodies should and could be lived (Overboe, 2007). A postconventionalist views non-normative bodies not as invalid or lacking, but in terms of affirmation, possibility and becoming (Braidotti, 2003). To what extent then could deviations from normative, taken for granted ideas of being 'mentally healthy' be seen not as pathological but as possibility? To what extent can critical disability studies embrace different kinds of activism that, for example, challenge normative standard ways of living a 'good life'? How can we celebrate and include different forms of communicating resistance and activism? What can critical disability studies theory learn from critical mental health activists and practitioners about issues of interdependence, community support and peer advocacy? I would like to end this paper with the words of a disability activist, who would like to remain anonymous, and their response to an email I sent out to the disability research mailing list asking for examples of 'the psychopathology of the non-disabled'. This account I think starts this process of thinking about the interconnection of disability and mental health as a possibility rather than a complication:

> With cognitive disabilities like mine, people do not immediately see our disability. So when the symptoms show up, people think we are weird, immature or rebellious, and they avoid us or pass judgement. They attribute our inability to a lack of character.
>
> For people whose disorder makes them behave in a way that others think is inappropriate, they get told they are spoilt or rebellious. I have even been judged like this by the police

when my parents abused me because they did not understand my disability and my way of thinking.

People have told me my behaviour and my problems are my fault, and that I'm not trying enough. Who are they to judge that? Only I and the people who live with me will be able to know that. Before I was diagnosed, I thought I could control my thinking and behaviour better if I tried harder. But it never helped, and my efforts only caused me endless frustration, decreasing my confidence. When I was diagnosed I realised that I was fighting a losing battle in that regard.

Sometimes when I tell someone about my condition and my symptoms, they tell me, ""There's nothing different about you. We all do those things from time to time. But if they bothered to read about my condition, they would see that I am wired differently neurologically compared to other people. And it is the combination of symptoms which limit one's functioning in life and last a lifetime that constitutes a syndrome.

When explaining to someone, it is very offensive to be told, ""You're just making an excuse for your behaviour". This is a very common remark I get. But people would never say that to a person with a physical disability, would they?! So why say it to a person with a neurological disability.

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The social re-framing of forms of mental disorder

David Pilgrim and Floris Tomasini

The track record of psychiatric patients forging a common cause with those with physical disabilities has been weak and patchy (Beresford *et al.*, 1996; Mulvany, 2000). The demonstrated discrimination against physically disabled people has emerged in societies that have not adopted enabling policies to improve social inclusion. In the case of mental health problems, social exclusion is *actively justified* on grounds of un-reason. Indeed, a whole legislative apparatus is constructed to ensure and oversee that social exclusion; an arrangement deemed to be socially progressive.

It is *because* people with mental health problems are deemed to be inherently unreasonable that others assume that they should be 'justifiably' subjected to unequal treatment: their rights for equal treatment are held in abeyance, until they are deemed less of a risk to themselves and others. This is not then an expression of political ignorance and neglect (as has been the case often in relation to physical disability) but a deliberate and highly considered aspect of social policy.

Professionals and lay people

During the 19th century, to be unreasonable became a focus of interest for State-sanctioned medical authority. It was also grounds for seemingly legitimate suspicion and rejection from those who were sane by common consent. The history of social control is not merely about the State and its agents; ordinary people exercise their own forms of powerful informal labelling and control. The decision making about mental health problems occurs in the lay arena of the family and the street, with professionals usually rubber-stamping decisions *made already* by others. As the case for the legal legitimation of this bottom up social control emerged in the 19th century (with lunacy legislation), the sane were anxiously mindful of their fate. Bean (1986) notes that one of the main aspects of lunacy legislation debates was the importance of avoiding 'unfair detention'; the sane understood all too well what degradations and losses of liberty were linked to insanity. This tension remains today: if 'access' to mental healthcare is so desirable, why do we need legislation to enforce it and protect us against the deprivations and risks in its wake?

Social psychological nuances of rejecting unreasonable in everyday modern life

The political implications of being unreasonable in modern society are nuanced, not simple: labelling, stigma and control, are complex, intimate or 'micro-social' context-dependent, matters that emerge in everyday settings *before* agents of the State even assess them ('diagnose') and intervene ('treat'). Moreover as Szasz (1963) notes it is not being dangerous that is at issue here but 'the manner in which one is dangerous'. This matter of social judgment and its role in the construction or emergence of mental health problems in the lay arena (i.e. before formal psychiatric codification) has been central to sociological understandings of mental disorder in the wake of Goffman's seminal work. He noted that we are all expected to make sense of our actions to others in the wake of transgressions about rule following behaviour that respects the rights of others in everyday life to go about their daily business untroubled (Goffman, 1963).

Nuance 1-risk to others

Risk to others is a central factor in decision making by lay people in public and privates spaces and continues to be so, once mental health professionals take charge of the decision making. Madness like its complement in society ('mental normality') contains forms of anti-social action ranging from the benign but irritating to the actively dangerous. For example, cold-callers selling replacement windows or 'Chuggers' enlisting support for charities on the high street are at one end of this spectrum and drunk drivers and violent criminals are at the other.

Prospective powers to control risky action are enacted by the State in a highly discriminatory fashion. Boxers and mercenary soldiers set out to inflict harm on others but they are deemed to be

sane, whereas others who act in a harmless but unintelligible way may lose their liberty without trial. Again there seems to be inconsistency in the way we perceive risks to others. Logically, if this really was a primary concern, the state could pass a draconian law which set a curfew for all under 30s to be off the streets, between dusk on Fridays and dawn on Mondays. Many lives would be saved from the reduction in road traffic accidents; rates of sexually transmitted diseases and unwanted pregnancies would drop, as would the rate of sexual offences and violence against people on the streets and in domestic settings.

Nuance 2-risk to self

Preventing risk to self is one rationale for current 'mental health law'. The State can intervene to prevent self-harm and suicide using this power. However, suicide in most countries is not illegal and people who are *not* considered to be mentally disordered might be obese, smoke cigarettes, drink alcohol excessively and indulge in unprotected sex. Racing car drivers have high social status and rock climbers are envied for their courage. Young people habitually pierce and tattoo their bodies. Why then do we control some people who injure or mutilate their bodies or act in a way which endangers their wellbeing but not others? Thus the issue is not that people jeopardize their health but the way they do this and in which context; it concerns the discriminatory judgments about the manner in which risky action manifests in society.

Nuance 3 - Self-centeredness and the impaired recognition of others

We are all *to some extent* self concerned, but some of us are more than others. When the latter emerges then people with mental health problems are produced by social judgements of onlookers or 'significant others'. This is about the infringement of what Thoits (1985) calls 'emotion rules'.

When we turn to those deemed to be 'personality disordered', then their self-centredness is not merely a by-product of their mental state (say of madness or extreme fear) but actually *constitutes* that state on a regular basis. Their needs dominate their relationships with others and others are used as a means to an end to gratify needs. Occasionally this type of habitual self-centredness is socially tolerated as a form of 'blindness' to reasonable behaviour at the expense of full role achievement, as in the successful business man who manipulates others to acquire success, fame, power or remuneration (Babiak and Hare, 2000).

Discussion

Where does all of this leave people with mental health problems, individually and collectively? At the individual level to lose one's reason can have profound and long term implications (Ingleby, 1981). An implication of this precarious outcome at the individual level is that *collective reasonableness* can be developed and advanced by people with mental health problems. This is why the social movement of 'survivors' remains so important. However, our focus here is not on those reasonable demands but on whether or not they might be aligned with demands from people in the physical disability movement.

One option is for the movement of psychiatric survivors to abandon that ambition but to explore more differentiated demands within its ranks. For example, the demands of those who know over time that they act in an unintelligible way may well be different from those who are recurrently unhappy and in turn would be different from those who recurrently have difficulty in maintaining mutually acceptable relationships with others.

Broadly, a second option is for the survivors' movement to press on with an attempt at aligning itself conceptually with the social model of disability to practically and politically resolve the equivocation on both sides to date. This prospect is more likely to succeed in relation to what is often called 'mental distress' but it may be a challenging negotiation when the social consequences of risky behaviour or incorrigible conduct are addressed.

If either of these future scenarios were to emerge then this paper has attempted to offer some reflection about the underlying complexity of the matters relevant to their negotiation. At the centre of that reflection has been a suggestion that unreasonableness should be reformulated in a more analogue and less digital way. On the one hand this preserves Goffman's common sense view of mutually accountable behaviour. Any transgression of emotion rules, but particularly the rule of intelligibility, would be at the centre of thinking through which political demands can work and which cannot. On the other hand it overcomes the tendency of the 'othering' of mental health problems.

It is quite reasonable for the survivors' movement to make the strongly persuasive point that all human beings are more or less irrational, more or less unhappy and more or less at ease with their fellows. In the light of these reflections, it might be possible to increasingly discover the character of a mentally enabling society. To what degree should madness and misery be simply tolerated? What are the best ways to use unhappiness constructively? What should (any of us) do when faced with people who recurrently act in ways that we consider unreasonably self-centred? When should risk to self and others be a concern and when should it be ignored? Should coercive solutions to risk be abandoned and what would be the consequences? If they are retained what are the consequences? These sorts of questions would then go beyond our current taken for granted routines based upon the combination of medicalised routines and legal measures of maintaining social order.

By discussing 'mental disorder' in such socio-ethical terms we are also forced to address philosophical questions about accountability and moral agency. We are left either accepting its expression as legitimate grounds for *excusing* unreasonable action in society (the position adopted by orthodox medical paternalists) or, conversely, we demand its *fully moral accountability* (the position adopted by Szasz in all of his writings). We might adopt a middle position but this must still be defended ethically.

If mental disorder is *excused* then paternalism and coercion legitimately displace a respect for full citizenship and warrant at times detention without trial 'in the patient's best interests'. This also means that (per tradition) we would simply find the views of those with a diagnosable mental disorder as precarious or discreditable. On the other hand, if mental disorder is *held to account successfully* then, in large part, it would no longer be mental disorder and there would be no grounds for either medical paternalism or so called 'mental health legislation'. This would mean though that those with a diagnosable mental disorder could not legitimately special plead for privileges (such as specific welfare payments). We would listen to their views credulously as much as we would anyone else (i.e. we would not automatically discredit their opinions).

A more consistent and non-discriminatory approach would require that we are open about moral questions both about how as a society we wish to ensure compassion for those who are distressed alongside reasonable expectations of culpability for all citizens. Compassion and culpability could be debated by all of us in order to go beyond our current contradictory legal arrangements, which manage to be both too punitive (by removing liberty without advocacy or trial for those committing no criminal act) and too ready to excuse (by removing responsibility for those outside of our moral order, who are bad or mad by common agreement).

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Alliances and communicative action: one possibility for reframing theory and praxis

Mick McKeown

Introduction

The papers by Plumb, Beresford and colleagues, Thomas, and Spandler and Calton which were a point of departure for the symposium are replete with both the complexity of competing ideas for framing the theory and politics of mental health survivor identity in a context of wider 'disability' struggles and the sense that activism for change is paramount. Different theories or means of making sense of the social position of mental health survivors have the potential to underpin movement activism. Questions arise over the extent to which different understandings, and the means by which they are arrived at, might foster solidarity or division with potential allies. This paper will not directly seek to develop critique of the merits or otherwise of social models of disability for the mental health context. Rather, it will explore understandings of ways by which individuals and groups might take part in discussion and debate to arrive at more agreeable theories or politics of mental health. A critical look at Habermas's (1986, 1987) theory of communicative action will be developed and its relevance for this context discussed. The idea of the university as an interesting social space for deliberations on movement politics and theory will be highlighted, bringing together movement activists and critically engaged academics.

There is a mixed history of this sort of coalition building with some notable examples of constructive dialogue and action over the years. The main arguments put forward here are twofold: First, university spaces, populated by critically engaged academics, might afford creative opportunities to forge political alliances at the same time as working through the complexity of debates about the politics and theory that can sustain action. Second, the action which proceeds beyond talk to advance political and social objectives relevant to mental health and people's lived experiences could and should mobilise actors across a range of social movements and progressive organisations, including the trade unions which organize public sector workers. Arguably, this need not dilute or co-opt the survivor movement voice but this is a threat that must be considered and countered.

Habermas's theory of communicative action has been expounded and critiqued at length, and there is not room here to revisit most of this in detail. Suffice to say, certain authors have recognized the possibilities of an 'ideal-type' communication, unconstrained by unequal power relations, respectful of difference and grounded in reason as a vehicle for enacting social change and associated with the sorts of prefigurative, deliberative democracies of certain social movements. Others have applied this thinking to analysis of mental health social movements and the notion of user involvement in arenas such as policy making and organization of health care services.

University space

A general policy trend to support service user involvement has been matched in university contexts. In my university, for example, the Comensus initiative supports a range of individuals and groups across a wide spectrum of personal experience of use of health and social care services (or refusal to make use of some of these) to participate in the education of health and social care practitioners and engage in associated research projects. This sort of activity is replicated in different forms and with different degrees of intensity across the higher education sector. Though, at present, precious few of these are hotbeds of activism, there are moments when such a possibility shows its face. Many of the participants who enter universities to interact with students or academic staff *are* activists in other parts of their life, and these people value the opportunity to attempt to change the future of services by influencing the hearts and minds of student practitioners.

Pre-dating this, has been a tradition in universities for the emergence of public intellectuals. A simple view of this notion, however, need not move beyond possession of a radical worldview and

an inclination to pursue those ideas within and beyond the academy. In its most limited sense the degree of *activism* is restricted to writing and speaking and may not extend to actual embodied solidarity with movements. Alternately, certain academics, perhaps less well known than the major public figures, are more actively engaged and attempt to align their intellectual interests with the realisation of movement goals.

Movement activists do not need scholars to make sense of their actions and tactics. Though some academic theory is undoubtedly useful, when academics adopt a critical pose this can merely be self-indulgent (Drury 2003). Critical scholars become useful for movements when they can engage with or provoke debate *within* movements beyond academic circles (Biglia 2003). Various commentators have applied similar reasoning to survivor politics and movements. Cresswell and Spandler (2011) utilise Barker and Cox's (2002) deployment of Gramsci's distinction between *organic* and *traditional* intellectuals to coin the term *critically engaged academics*, highlighting a valued positioning wherein university personnel assume both an academic and activists role at one and the same time. Crucially, these authors highlight the experiential contradictions and overall *unsettled relations* that arise for academics who choose to have a *foot in both camps* (see also Bannerji et al. 1992, Church 1995, Hale 2008).

One possibility is that survivor movement activists enter the university in a context of involvement and encounter critically engaged academic allies. In such a scenario there is the possibility of making much more of the potential for involvement to pursue radical ends. Of course, this is not an argument that survivor movement politics are necessarily best served in a university context nor that other domains of contention, especially clinical practice, should be left alone. Rather, university space might be *one* place where activism can be brought to bear. Tutors and researchers with a background in clinical practice remain somewhat protected from direct association with statutory power or service provision. The fact that this may be more symbolic than actual does not deny the possibility that the academic role and setting might afford more potential for nurturing trust between staff and service users than may exist in, for example, service settings. This is not to say that positive relationships do not exist between staff and service users in practice settings or, indeed, that movement alliances cannot be enacted. Rather, the social relations in practice can be coloured by the operation of legislative powers, not least compulsion into services and the organisation of practitioners' work may militate against having the necessary time to invest in non-clinical conversations about, for example, movement politics.

Despite this, there are numerous instances of positive and progressive therapeutic relations within services and opportunities for constructive political alliances between service users and certain practitioners. These have been noted to form in defence of services against cuts or closure (Cresswell 2009) or in a context of democratising service configurations, or when these circumstances coincide (Spandler 2006).

The university setting may also be better off for quiet, comfortable meeting space and can have access to other relevant resources such as information and personnel experienced in supporting community activism or empowerment via action learning or research. This might include access to sources of knowledge that offer different understandings of mental health than the mono-cultural biological psychiatry which dominates services. This is not an elitist point: there are plenty of sources of alternative knowledge external to the university, not least the experiential knowledge held by the survivor movement and universities themselves have a significant role in reproducing the culture in service settings through the education and training of practitioners. Rather, access to alternative knowledge *is* readily available in a university setting.

The view that universities might offer a productive social space for mental health activism mirrors other commentary on place and mental health service users. Different social spaces are more or less amenable to supporting involvement and engagement, and positive consequences of such activity include impact on *citizen subjectivities*, sense of belonging and a potential to dismantle exclusionary

relationships (Parr 2008). Crossley (1999) highlights the occurrence of particular transformations of social space in psychiatric settings that hold special appeal for user activists, are prefigurative of more progressive social relations and are associated with processes of legitimation and knowledge production: these he describes as *working utopias* or *laboratories of experience*. Spandler (2009: 677) discusses places of contention which might be either convergent or paradoxical spaces: *potentially creative spaces* where contradictions and conflicts can be faced and these tensions allow for the *articulation of difference* or acknowledgement of unsettled relations to the point where 'such expression opens up new spaces of resistance by imagining an elsewhere and expanding prefigurative social relations'. Arguably, the university setting might represent just such a space for engaging with survivor activism.

The university as a social space for alliance building
It should be noted at this juncture that survivor activists may be sceptical or even hostile to the idea that university settings have anything to offer their movement. Many will not need the academy for access to knowledge; either preferring knowledge forged in experience, which may not be wholeheartedly endorsed in academic circles, or being self-reliant in plotting personal learning, akin to the labour movement identity of *auto-didact*. A corollary of this is that critical engagement between university personnel and community activists must be as much about transforming the academy as it is about realising movement goals (but, if the target is psychiatric knowledge, for instance, some of both can possibly be achieved). The critically engaged academic typically has modest claims for their personal contribution to any movement, but has an interest in both supporting the movement and seeking changes to the organisation and social relations of the university.

It has been argued that where survivor activists engage in formal involvement opportunities with health care provider institutions and policy makers the conditions for truly unconstrained communication are never fully realised, and key topics of interest can be closed down or completely off-limits (Hodge 2005a). Thus, the Habermasian threshold ideal of freeing up communication and evening out power imbalances as a precursor for communicative action is not reached. Alternately, Godin and colleagues (2007) deployed Habermas's theory in reflecting upon a research study bringing together academic staff and service users from secure psychiatric care in university settings to plan and participate in research activity and also engage in the university's public sphere of academic seminars. These authors conclude that there is a difference between university settings and forensic care environments in the extent to which open communication can take place – the crucial enabler being the participatory approach contrasted with forms of institutional social relations in the hospital settings better described in terms of instrumental or strategic communication. Furthermore, it might be the case that progressive academics, who have a critical disposition towards psychiatry and the politics of mental health need not necessarily feel constrained by defensiveness about fundamental critique of services provided by service users. Again, Spandler's (2006) account shows that critically minded staff allies of the user movement are not unique to university settings. I would argue, however, that it is on the whole *easier* to express critical ideas in a university rather than a service context.

There is an issue of scale when critically applying Habermas's ideas and, on the face of it, the notion of rationality would appear to be implicitly problematic when considering the psychiatric survivor movement. When considering a movement territory made up of small and disparate groups, it can be argued that neither consensus nor rationality need be necessary for social action or change to take place. This might especially be the case for mental health activism where consensus over the complexity of available perspectives is difficult to achieve and rationality itself is contested. Much social action is as much replete with emotional rather than reasoned responses to perceived disadvantage or oppression (Taylor & Whittier 1995, Jasper 1997, Barker 2001). In this vein, feminist critique of Habermas's ideas contends that the emphasis on *reason* is masculinist and downplays the importance of factors such as care or kindness.

These factors, however, are very much of relevance to prefigurative, relational forms of organising and activism and have been remarked upon explicitly by Comensus participants (Downe et al. 2007, McKeown et al. 2010). For example, service user participants in Comensus report how their involvement affects students and their own sense of identity. Whilst some of the transformative changes to services which participants aspire to are postponed or difficult to demonstrate, small, but nonetheless profound changes in individual relationships are reported. More often than not this is articulated in terms of moving people emotionally (McKeown et al. 2010, McKeown et al. forthcoming). Garlick & Palmer (2008) develop the work of Bauman (1995) to explore this idea of relational forms of organising: 'an ideal form of togetherness ... of community engagement between universities and centres of community activism'.

The *rationality* problem

Habermas's emphasis on rationality is of concern for activists, with a lengthy history of the silencing and marginalizing of survivor voices on the grounds of irrationality (see Campbell 2009, Bracken & Thomas 2001, Hornstein 2002). Mary O'Hagan (1986: 32) noted in the 1980s how the voices of people with direct experiences of service use were silenced in both scholarly settings and wider society; their views were effectively 'seized by the reality regulators and put under lock and key in seclusion' mirroring experiences in services.

One of the rhetorical strategies of the survivor movement has been to resist psychiatric models and explanations for different experiences. Similarly, prevailing conceptualisations of self and other are disputed, as psychiatry is challenged for defining the boundary that divides sane from insane, normal from abnormal. Habermas's concept of systematically disordered communication uses psycho-pathology and psychoanalysis as its analogues (see Habermas 1979), further complicating the appeal of his theories for movement activists. He also talks about communicative competence as a pre-requisite for meaningful dialogue (see Habermas 1990), potentially providing further ammunition for those who would discount certain contributions. Weinberg (2007) makes this point regarding problems with Habermasian theory in accounting for the position of learning disabled individuals in a context of user involvement. Clifford (2009) goes further to suggest that the embodied nature of communication, including non-verbal expression, is specifically excluded, and that the appeal of communicative action theory for various forms of disability activists, including mental health survivors, could be extended by appropriate revisions bringing in notions of inter-dependence and shared vulnerability as counterpoints to simplistic autonomy and rationality. Hodge (2005b) points out that oppression also takes place within the inter-subjectivity of the lifeworld, where the otherness identity of being a mental patient thrives, user voices are discredited, and possibilities for communicative action are limited. Lewis (2009) makes similar observations on the ways in which service user identity suffers from status subordination diminishing possibilities for parity with professionals in any dialogue, and that this is effectively a human rights issue. However, despite negative consequences of being denied opportunities to communicate freely in the mainstream there may be a certain advantage in identification with an oppressed group because: 'The oppressed are free to know differently' (O'Hagan 1986: 40).

Taken together, this critique poses some serious questions regarding the applicability of Habermas's theory to the context of survivor movement communications. Yet Habermas is also keen to stress the importance of relational aspects of his communicative action, its potential for achieving progressive social change, and an appeal to include the marginalized and challenge oppressive consequences of *othering*. Gardiner (2004) argues that Bakhtin's ideas can be used to improve Habermas's theory by tackling some of the overly abstract features, acknowledging more plurality in the public sphere and rendering the whole less inimical to *difference* and the complexities or multiplicities of everyday speech for ordinary people. Different views, different ways of making sense of the world need not be seen as essentially irrational just because they are voiced by a survivor. Furthermore, dialogue within movements must achieve some degree of clarity of expression and comprehensibility to others to take the movement forward: arguably, it is equally

oppressive to deny capacity for rationality to the person deemed *irrational* by psychiatry. Coleman (2008: 341) charts the extent to which psychiatric survivor activists have 'significantly contributed to a reconfiguring of the relationship between madness and rationality' and 'forcefully nullified entrenched stereotypes of their incapacity through vibrant political expression'. She concludes that users of mental health services must be seen as holding 'a rational capacity to speak credibly about their condition and their treatment and ... the science of psychiatry'.

Conclusions

If we are to consider the university as a social space that supports forms of dialogue amenable to forging effective alliances between survivors and academics it would be naïve to pretend that these spaces are ideal, fully-formed, or that communication therein is completely open. A multiplicity of constraining factors also exist including questions over the sincerity of engagement and the risk of incorporation. The involvement tag itself is somewhat paternalistic and does not adequately encompass the activist roles and identities noted here. Nevertheless, if the development of such social spaces can be seen as a work in progress, then, arguably, such fora should flourish where a dynamic centre of survivor activism coincides with the presence of critically engaged academics. These endeavours may also open up the potential for developing movement knowledge that illuminates the complexities at stake in forging a new, more progressive politics of mental health or develops strategic thinking in relation to different conceptions of disability.

The realisation of such goals would also herald potential for academics to embrace new forms of identity and activism for themselves. Entering into alliances with service users and carers in a university context may be a first step towards further connections between scholars, community activists and other community groups realising a broader inter-relationship of politics, engagement and activism. Aspirations for transformative and redistributive goals may be beyond what can be achieved in any single institutional setting but need not neglect positive changes that can be enacted at the local level. A powerful movement for a more equal society, bringing together alliances of service user activists, practitioner staff, critically engaged academics, and associated trade unions is one possibility that does not have to be derailed by contradictory forces and tensions as long as these are faced up to. Habermas's theory of communicative action has much to offer when thinking about how best to organise prefiguratively for change within university settings but any aspirations for alliances or consensus ought be tempered by an appreciation that relations along the way are likely to be unsettled and unsettling.

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part four

Responses to Symposium

Trauma and the origins of distress and disability: complex causes, mobile meanings, and a new social model?

Alan Beattie

Starting point

The organisers of the Distress or Disability? seminar invited us to explore questions about the value of the 'social model' in reconceptualising distress or disability as 'psycho-social adjustment to trauma'. During the seminar, such questions (and the papers addressing them) provoked lively discussion, and raised further questions about the 'aetiology' of distress and disability. In this note I summarise thoughts that occurred to me during those discussions (and subsequently). I offer two interconnected ideas for moving on with the 'social model'.

1. New thinking about concepts of complexity and causation .

Trauma is a term widely used in health work, often with a strictly biomedical connotation (as in trauma surgery or accident-&-emergency medicine), and sometimes with a very different psychosocial connotation (as in the psychodynamics of early-life trauma; and in PTSD). In our seminar we perhaps didn't pay as much attention as we should to the 'traumagenic model' developed by Read and colleagues - controversial research which claims to develop a 'genuinely integrated biopsychosocial model' of the causation of psychosis and other mental health problems (and which has links to Lancaster and other universities in the NW). I will refer to this research, as part of my attempt to tease out the contested concepts of complexity that shape (in many respects distort) the study of 'causes' in epidemiological and aetiological inquiry.

For those involved in health research and action in settings where biomedical sciences predominate, the science of complex systems is often seen as a way to get beyond the 'silver bullet thinking' inherited or borrowed from earlier successes in the biopathology of physical trauma and in the microbiology of infectious diseases, ie beyond one-step, linear, mechanistic chains of causation. Complexity theory has become a source of alluring new models and metaphors, not least in epidemiology, where 'theory wars' sparked by competing models have led to this discipline being described as 'a thought-tormented world'. When I taught the subject (I no longer do) I designed my courses around what I see as four distinct and contested concepts of complexity in aetiological investigation - each of them characterised by a core metaphor.

These can be summarised as follows (for a fuller account see Beattie 2004):

1. 'black box'. This is seen in *multifactorial models* which focus on the plurality and diversity of risks to health arising in ways of living; they use linear regression methods to measure how risks 'add up' (and multiply) to cause specific diseases. This is the classic - but most minimal - departure from a 'silver bullet' metaphor (in this context, single-gene causation) – multi-factor models still address a single level of analysis, and still deploy linear and mechanistic assumptions about causal interactions (Fig 1). It is seen in 'bio-bio-bio' models that proliferate and elaborate the lists of factors (eg genetic, biochemical etc) to be taken into account; and even in some bio-psycho-social models - which take more diverse 'factors' into account, but leave the 'interactions' between them unspecified and unexplained (hence 'black box'). Models of this sort (alongside silver bullet models) continue to dominate news reports of 'epidemiological breakthroughs' in academic research. Read & Sanders (2010) review evidence that across the world, the general public (lay people; patients) largely adhere to a multifactorial view of the causes of mental illness (perhaps ahead of some more biologically-inclined psychiatrists/psychologists).
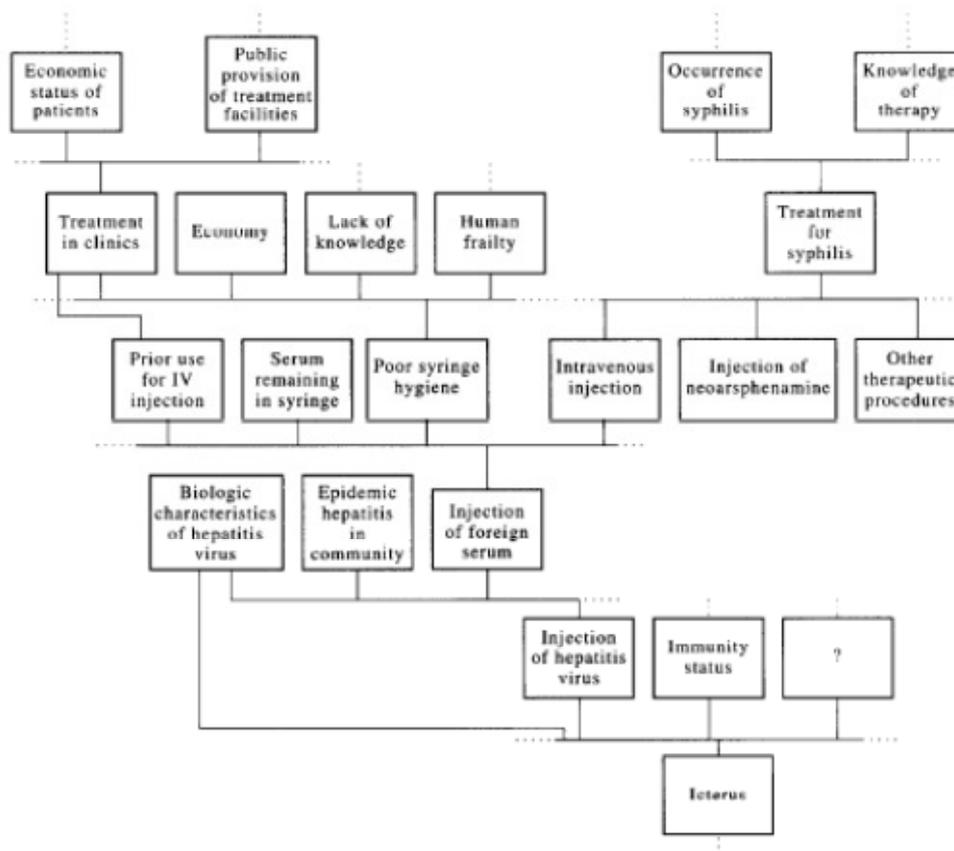
Fig 1: 'Risk factors in the association between syphilis and jaundice' (McMahon et al., 1960)

2. <u>'Chinese box'.</u> This is seen in *multilevel pathway models* which focus on factors playing across a concentric set or hierarchy of levels (both individual and environmental; both physical and social) and how they accumulate and intersect during the *lifecourse* to cause specific diseases. These models use multivariate statistics (in the form of multilevel analysis and path analysis), and are welcomed by some for their promise to bring together molecular genetics, post-genomic biology and social ecology, to create new insights into the origins of health inequalities. Most however rely on the same linear, deterministic causal thinking as 'black box' models; and they have difficulty in resolving how to combine and extrapolate and weight factors across different levels (Fig 2), also in explaining the interactions between levels (Fig 3). Two partial exceptions are the explanation of suicide based on Durkheim's theory of the sociology of community versus anomie (1897), and the explanation of the origins of depression in women based on the 'adverse life events' theory of Brown and Harris (1977); both of these are multivariable, multilevel models, but both also make initial attempts to explain the interaction between levels in psychosocial terms (especially Bowlby 1988; Harris 2003: see Figs 4, 5). Recent attempts by Read and colleagues (2001, 2008, 2010) to explain 'pathways between levels' are centred on a cognitive perspective that gives less attention to ecosocial or other kinds of structural depth than did Brown and Harris (1977) in their original formulation of the 'life events' approach - as so often, the 'S' in the BPS (biopsychosocial) model is relatively silent (Figs 6, 7).
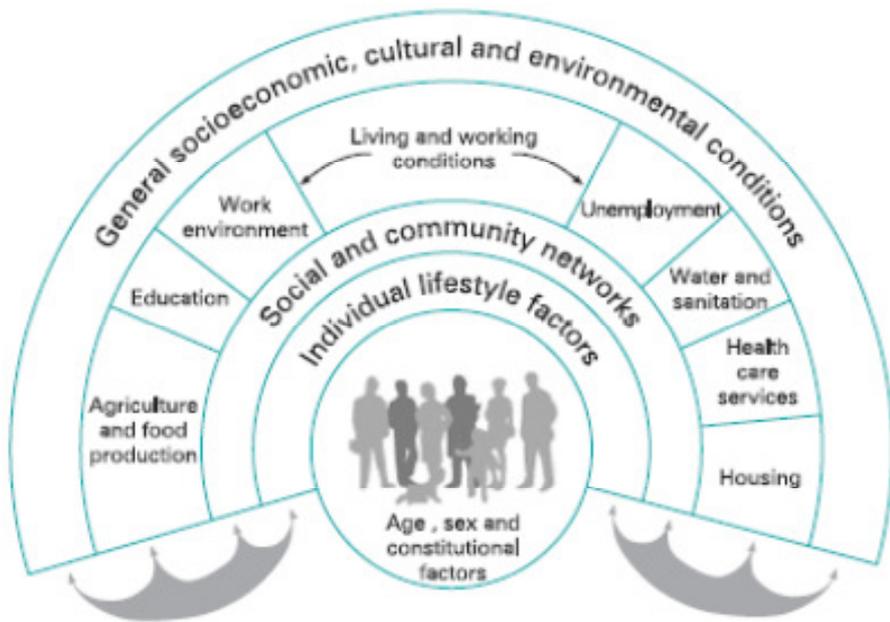
Fig 2: Levels in the social determinants of ill-health (Dahlgren and Whitehead, 1992)
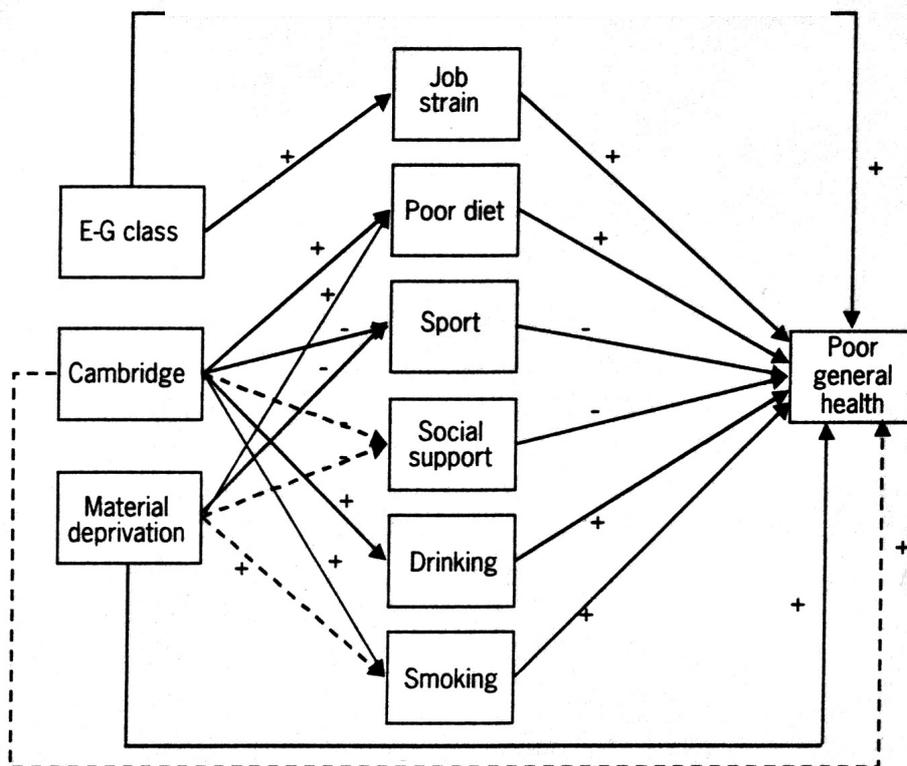

Fig 3: Association between housing tenure and health inequality (Macintyre & Ellaway 2000)
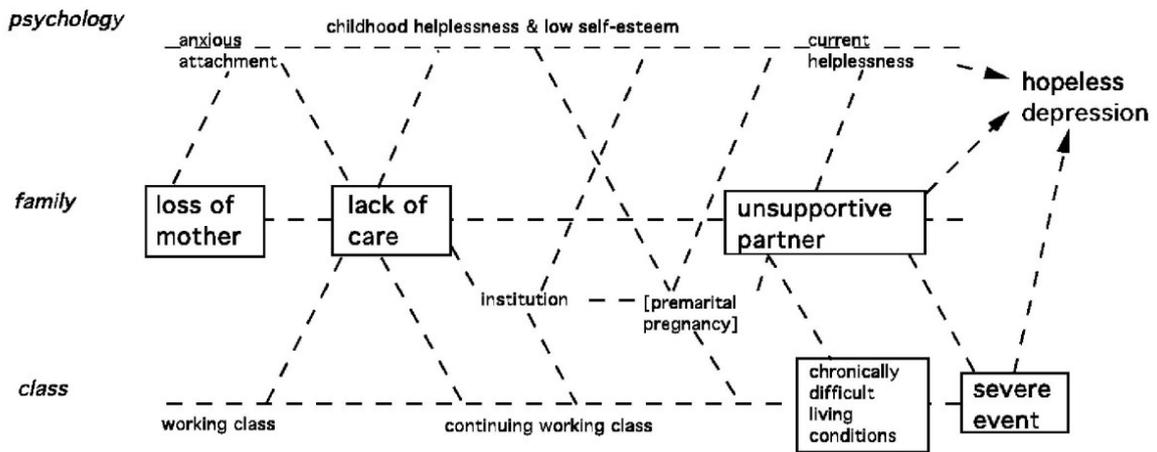
Fig 4: Psychosocial pathways to depression in women (Bowlby 1988)

Strand –1 External Socio-structural

Socio-Economic Status (SES)   SES

Childhood Adversity   Early Adult Adversity   Recent Adversity

Ongoing Social Support   Poor Social Support   DEPRESSION

Strand-2 Internal Psychological

Childhood Helplessness/ Mastery   Attachment Style /Personality Disorder   Coping Style

Low self-esteem   Low self-esteem

Strand 3 Internal Physiological   Genetic endowment • • • • • Hormonal Factors • • • • • • • • • •

Fig 5: Psychosocial pathways to depression in women. (Harris 2003)

Poverty, urban living, unemployment, social isolation, discrimination etc. (frequently intergenerational)

Abuse
Neglect
Parental loss
Subtle relational trauma
(frequently intergenerational)

Insecure/ Disorganised Attachment

Problems with:
Cognitive schema
Mentalisation
Affect Regulation
Relationships
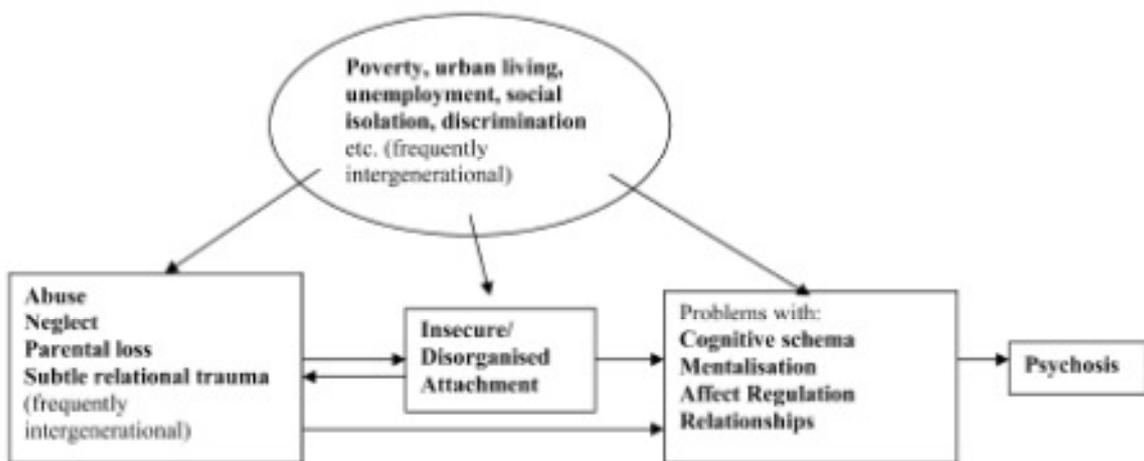
Psychosis

Fig 6: Relationships between childhood adversity and psychosis (Read & Gumley 2008)
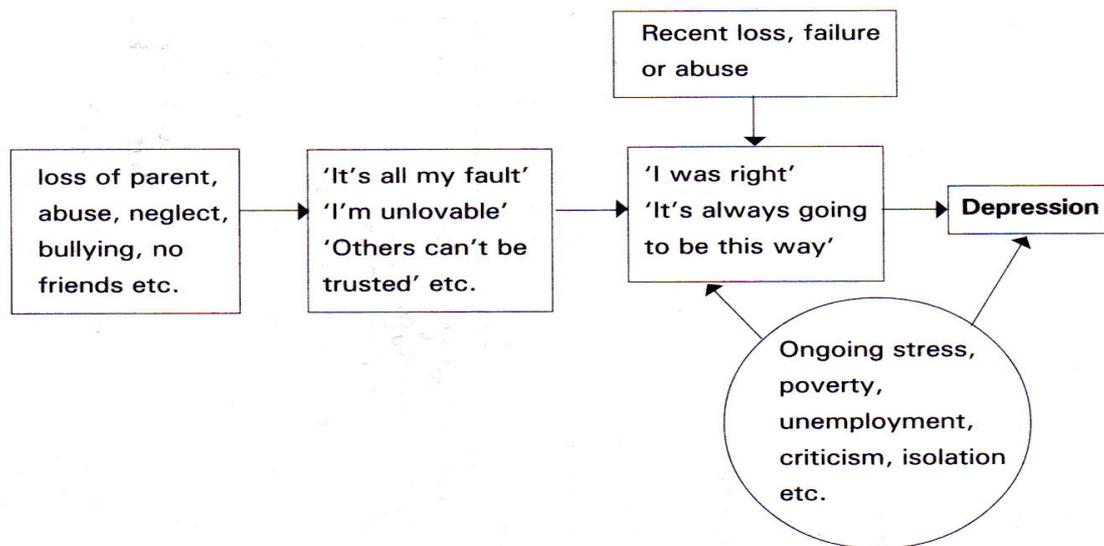
Fig 7: Relationships between trauma, loss and depression (Read & Sanders 2010)

3. 'epigenetic landscape'. This metaphor has just begun to get a mention in connection with *multiagent models* - rare in epidemiology - that offer a way of viewing the dynamics of individual and population health through concepts from complex developmental systems theory (Taylor 2011; and see Figs 8, 9). Here the black box or Chinese box is replaced by a model of human development as a programmable object that - in response to changes in inputs (at any level) - may shift into a set of 'fractal' alternative stable channels (bifurcations on attractor surfaces), picturing diseases as states that emerge when development is shunted into trajectories that have a reduced (fractal) plasticity of response. Such a model has been found useful in the study of epidemic outbreaks; but it will be even more illuminating in studies of how genetic variation, environmental inequalities and social gradients interact along the lifecourse to unfold into semi-stable disordered states. Read et al (2009) have extended their model to encompass 'epigenetic mechanisms' alongside 'adverse life events', but they fail to move decisively beyond the Chinese box paradigm (Fig 6, 7 above). One model that does so is by Krieger (Fig 10 below).
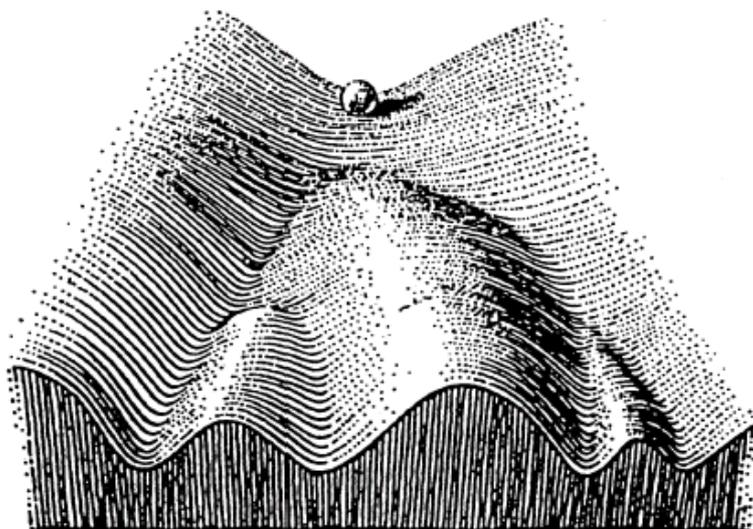
Fig 8: the epigenetic landscape (Waddington 1975)
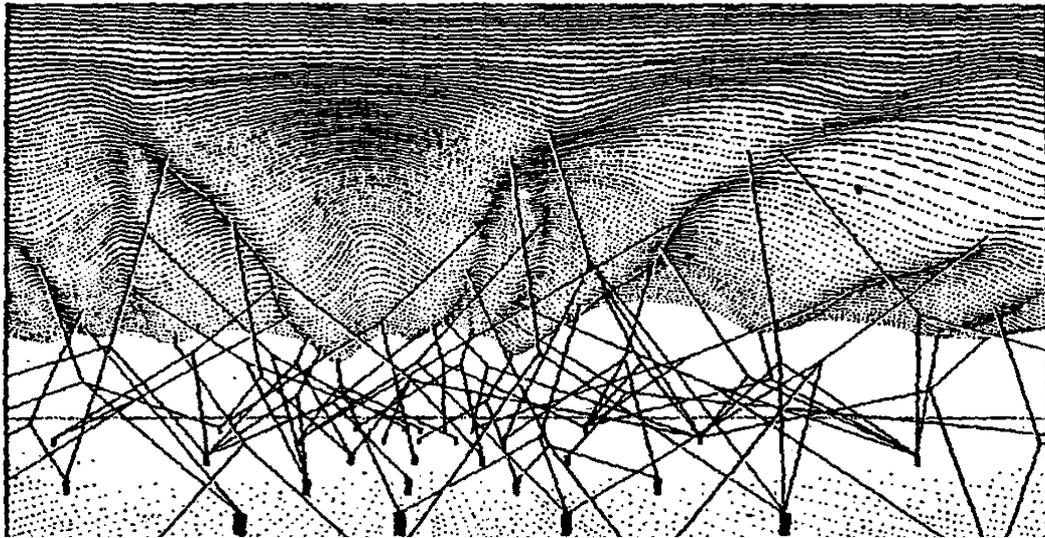
Fig 9 system of interactions underlying the epigenetic landscape (Waddington 1956)
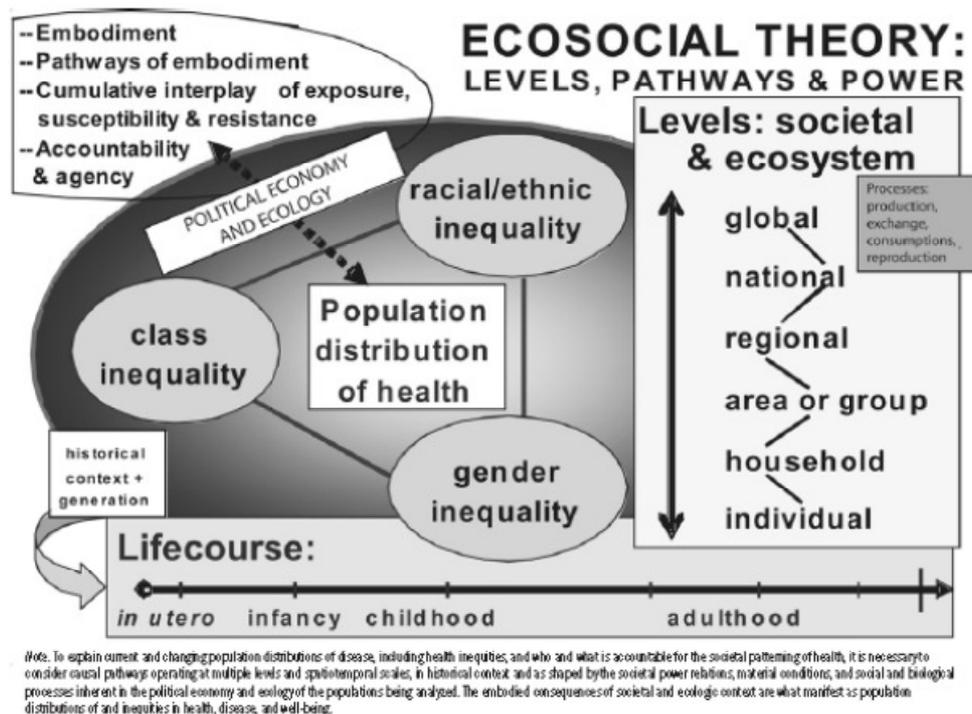
[Fig 10] Ecosocial model of origins of health inequities (Krieger 1994, 1999, 2004, 2008)

The central question for ecosocial theory is:

"*who and what is responsible for population patterns of health, disease, and wellbeing, as manifested in present, past, and changing social inequalities in health?*"

The model is multilevel/ multitemporal/ multicultural/ material/ embodied and it envisages 4 intertwined strands of 'macro-to-micro' causation (a 'fractal bush'):
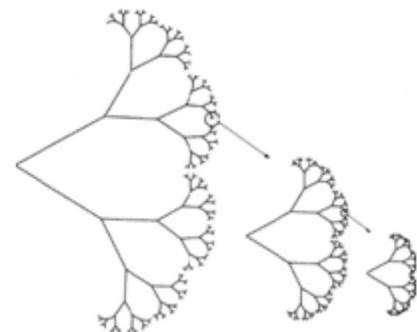
Krieger's ecosocial model *[précis by Alan Beattie]*

To aid conceptualisation, ecosocial theory uses a visual fractal metaphor of an evolving bush of life intertwined with the scaffolding of society that different core social groups daily reinforce or seek to alter. A fractal metaphor is chosen because fractals are recursive structures, repeating and self-similar at every scale, from micro to macro. Thus, ecosocial theory invites consideration of how population health is generated by social conditions necessarily engaging with biological processes, at every spatio-temporal scale, from subcellular to global, from nanoseconds to millennia.

The core concepts of ecosocial theory are:

a. **Embodiment**, a concept referring to how we literally incorporate, biologically, the material and social world in which we live, from in utero to death; a corollary is that no aspect of our biology can be understood in the absence of knowledge of history and of individual and societal ways of living.

b. **Pathways of embodiment**, structured simultaneously by (a) societal arrangements of power and property and contingent patterns of production, consumption, and reproduction, and (b) constraints and possibilities of our biology, as shaped by our species' evolutionary history, our ecological context, and individual histories, that is, trajectories of biological and social development.

c. **Dynamic and cumulative interplay between exposure, susceptibility, and resistance**, expressed in pathways of embodiment, with each factor and its distribution conceptualised at multiple levels (individual, neighbourhood, regional or political jurisdiction, national, inter-national or supra-national), and in multiple domains (for example, home, work, school, other public settings), in relation to relevant ecological niches, and manifested in processes at multiple scales of time and space.

d. **Accountability and agency**, expressed in pathways of and knowledge about embodiment, in relation to institutions (government, business, and public sector), communities, households, and individuals, and also in relation to the accountability and agency of epidemiologists and other scientists for theories used or ignored to explain social inequalities in health; a corollary is that, given likely complementary causal explanations at different scales and levels, epidemiological studies should explicitly name and consider the benefits and limitations of their particular scale and level of analysis.

4. 'ecosemiotic matrix'. (*I now consider 'matrix' to be far more appropriate than the term 'web' that I used in 2004).* This metaphor is only just now being hinted at on the edges of epidemiology in *(multi)narrative models* that address the 'linguistic' modes of complex systems (alongside their dynamical modes), as seen in studies of 'bio-social translation' (eg how stressful life-events have different meanings for different individuals); in the ecosocial anthropology of 'social embodiment' (eg how ill/wellness; distress; disability etc are differentially coded and contested in different cultures); and in popular & lay epidemiology (eg how groups and communities offer their own distinctive accounts of 'threats to health' in specific localities). This model could be extended by analytical frameworks borrowed from analogous systems: biosemiotic models of signalling processes in developing organisms (Jablonka & Lamb 2005; Wheeler 2006); information-space models of knowledge-management in 'learning organisations'; and models of 'multimodality' in texts and discourses (in critical social semiotics of the media). Though they are not declared explicitly, some facets of Krieger's ecosocial model also entail semiotic processes (notably cultural-historical pathways of embodiment). The richest development of the model may be achieved by incorporating insights from psychodynamic, phenomenological and post-Lacanian approaches to trauma (Ussher 2000; Wirth-Cauchon 2000). In a study of 'community beingness' in the aftermath of the closure of a steelworks in South Wales, Walkerdine (2010a, b) gives a complex account that mixes a sociology of trauma (Erikson 1994) with a psychoanalysis of the ways in which trauma is translated into subjective meaning and affect - through resonances and refigurings across a matrix of borderlines and 'encounter-events' (Ettinger 1992, 2006).

'Complex causes' as a paradigm nearing the end of its useful life?

It need come as no surprise that new understanding of the aetiology of distress and disability may be shaped (perhaps driven) by metaphors. The same has been noted generally of advances in

psychiatry, in medicine, in psychology, in the life sciences, in the natural sciences, and in the social sciences. One of the most valuable areas of common ground and joint effort for movement activists from the fields of mental health and of disability may be to give creative and critical attention to developing and using new metaphors. At the least it is important to be alert to the different epistemologies and ontologies that different models and metaphors entail: the linear, mechanistic reductionism of single-cause (silver bullet) models; the residual determinism of non-linear 'multifactorial, multiscalar, multitemporal' models; the stochastic indeterminism (and residual intransitivity) of agent-based epigenetic landscape models; the material-*cum*-discursive dualism and transitivity of ecosemiotic models. Moreover while the 'complexity turn' is still new in some areas of academic and activist thinking (and it can still bring fresh insights), in (what I call) 'the ecosemiotic matrix model' we probably see borrowing from complex systems thinking reaching its limit of usefulness.

In the life sciences, in medicine and in epidemiology, there is a danger that in trying to open up new 'trading zones' between the quantitative-statistical tradition and non-linear, narrative-based approaches the latter can only suffer violent distortion. Concepts like multiple narratives, multimodality, matrixial borderspace can probably be taken forward far more productively in the context of the social sciences and humanities - perhaps aligned with the idea of 'social autopsy' (Klinenberg 2002; Law & Singleton 2004). My own view is that the recent 'mobile turn' affords an especially promising new paradigm for redirecting research and action on 'trauma and the origins of distress and disability', and for taking the debate about the social model forward in provocative ways. A key clue is in the centrality of 'metaphor' to the advancement of understanding (as I've tried to show). The 'mobile turn' is not merely a source of new metaphors (travel, journeys, escape, flow, flux) – it is inavoidably concerned with 'metaphoricity' itself (Margaroni & Yiannopoulou 2006): the term 'metaphor' refers to a transfer, a transport of meaning: a metaphor is a vehicle that carries meaning from one domain to another. This is where my second argument takes off.

2. Moving beyond complex causes, towards mobile (mutative, shifting, movable) meanings.

Survivors' poetry (poems written out of their own mental distress, by people who have experienced the mental health care system as patients) is rich in 'metaphors of mobility' - wandering, travelling, dancing, escaping, being moved, journeys, flight, metamorphosis, transience, flux - they recur frequently and are often strikingly prominent. Such poetry can be crucial testimony for understanding trauma and the origins of distress and disability, and here I will place a number of poems alongside statements from the Mad Movement, to illustrate four issues:

1. searching for empathy

1. Mike Mosley   David Kessel (1991)

'There is a conspiracy against the social
democracy of the British common people'
Grey, calloused, forgotten at fifty,
he has given his all; his wiry heart,
his skilled locked fingers, his
chipped backbone, his broken welding
language, for this choking fag,
this dark blinding pint,
this scouring Irish lament.

Scorned, down for a bundle in bird,
forsaken by wives and the DHSS,
shy of nothing 'cept himself,

to this bare room, phlegm and loneliness
between stubborn slums and useless sirens.

Driven by fury to this back ward,
wasted, ulcered, unforgiving.

I start from here to make anew
the happiness of children playing
beneath heeding enduring gulls
in a wooded tempered land.

2. The Garden   Anne Marr (1996)

The tangled garden of my dreams,
I could bring to you.
I could show you, rain-beaded,
A spider's web of hope,
Trapping early sun.
A crazy path that curls through bowers,
Where spiky roses reach their hungry hands,
And tumbled ivy on the wall
Spills over the bruised moss.

I could tell you my desires,
And wrap the flawed net of my hopes
Around us both.

But you would run from the wilderness,
Wanting an ordered Italianate space,
Empty, and without me.

Poem 1 is by a survivor poet who himself used to be a GP; to me it illustrates the kind of empathy for a fellow-human that is exceedingly rare (and probably distressing in itself). Poem 2 is by a survivor poet; to me it captures exactly an experience of failed empathy. Two clinical psychologists observe: "Given our history of appallingly narrow ways of describing and understanding feelings and experiences traditionally labelled as mad, we need to start with an open mind and a commitment *not* to silence people's attempts to verbalise their distress and come up with their own solutions… *Empathy* is a powerful way of relating to people and helping them through personal disclosure, but it has been trained out of many professionals; members of the user movement seem much more aware of this…People will have to learn to live with a *multitude* of ideas about descriptions, causes and ways of alleviating distress (Newnes & Holmes). Poems may be a uniquely powerful medium for achieving this: 'embodied theories of meaning' refer to the way a poem can combine kinaesthetic, sensuous and emotional facets of experience (Johnson 1987; Lakoff 1998; Riley 2005; Turner 1991). One survivor-poet and activist argues that "Re-valuing the experience of distress is as important as re-shaping health services. Survivors may have special expertise to offer society as a result of their personal experience, *because of* rather than *in spite of* their life experiences – able, by reflecting on their own mental distress, to provide valuable new insights and approaches rooted in their direct experience, e.g. alternatives based on the values of *empathy, exchange, and mutuality*. Survivors' contributions can now move towards revised social understandings of distress" (Campbell). This is echoed in 'postpsychiatry':

"Too often professional models silence debate, or perpetuate monologues about madness. Whereas we advocate a new approach that will:

-Start with meanings, relationships & values, and the limits of our professional understanding.

-Set up multiple different sorts of dialogue about the meanings of distress and alienation.

-Favour 'multi-voiced' narratives that open-up meanings of distress or recovery.

-Accept contradictions, inconsistencies, ambiguities in the way a patient's identity is authored.

-Give the service user the right to negotiate how his/her reality is defined….

-Re-conceptualize distress to recognise the contextual factors that shape patients' experiences.

-Empower survivors to speak their own stories in their own words, in their own ways.

(Bracken & Thomas 2005)

2. articulating the runaway self

3. Admission   Emily Riall (2007)

There is a large expanse of dotted carpet
stretched between us. If I stare too hard at it the dots
start moving. Like beetles. My chair sags in the seat.
Someone's stubbed a cigarette out on the arm.

She fills in the boxes on her page
Age, weight, height. Various other pointless
bits of information that no one will ever
read again. Unless I go missing (NSR9).

I have already been through my history
but they will make me go over it again.
Apparently though everything is written down
no one can be bothered to read it.

I'm shown to my room. There's a window
covered by a curtain in the door.
That night I shiver under my hospital blankets listening
to the other patients shout down the corridor.

4. Glimmers of Light [excerpt] *Frank Bangay (1992)*

Alone in a city too big for comfort
too many people
too much loneliness
the spirit gets lost under the noise and clatter
you can become part of the crowd
and fade into insignificance
or you can express your craziness
and get singled out

Sometimes I want to escape from this competitive age but there is no sanctuary
just a return to the psychiatric ward.

We pay a high price in our search for enlightenment
Hiding in the shadows we feel safe
the world outside seems full of hostile images
a voice keeps saying
there are glimmers of hope
so keep on believing
one day your spirit will be strong again
one day your spirit will start dancing
                              dancing
                                    dancing

Poem 3 was written by a young psychiatric patient whose experience (described here) of lack of empathy in the psychiatric system led her shortly afterwards to take the classic escape route (she died by her own hand). Poem 4 is by another survivor-poet/activist, and provides a vivid account – almost a 'social autopsy' - of his own runaway self. Many other survivor poems describe being fugitive, lost, disoriented; soaring away on personal lines of flight. Sociolinguistics might note that the 'tenor' of such poems serves an *interpersonal function*, and is testimony to a desire to indicate a distinctive first-person position, to establish voice, role, and the polarity of relationships.

3. registering a runaway world

5. Leaving Hospital   Peter Street (1995)

Five months inside the shell of a WorkHouse/Asylum:
sixty years to paint over the smell of cruelty and
innocent faces they jammed between the bricks.

I want to be an undercoat for a little longer
and tell dirty jokes to the nineteenth century.
They're forcing me out into Now.

Into an upside-down inside-out Gulliver's world.
Where everything's changed
the streets, the cafes, the toilets.

6. To Carry the Child   *Stevie Smith (1953/2003)*

To carry the child into adult life
Is good? I say it is not,
To carry the child into adult life
Is to be handicapped.

The child in adult life is defenceless
And if he is grown-up, knows it,
And the grown up looks at the childish part
And despises it.

The child, too, despises the clever grown-up,
The man-of-the-world, the frozen,
For the child has the tears alive on his cheek
And the man has none of them.
As the child has colours, and the man sees no
Colours or anything,
Being easy only in things of the mind,
The child is easy in feeling.
Easy in feeling, easily excessive
And in excess powerful.
For instance, if you do not speak to the child
He will make trouble….

Oh it is not happy, it is never happy,
To carry the child into adulthood,
Let the children lie down before full growth
And die in their infanthood
And be guilty of no man's blood.

But oh the poor child, the poor child, what can he do,
Trapped in a grown-up carapace,
 But peer outside of his prison room
With the eye of an anarchist?

Poem 5 is by a survivor-poet, and captures the terror of an outside world that moves on too fast. Poem 6 is by a well-known poet who had episodes of self-harm; and it captures a similar kind of horror at an outside world that is out-of-step with a poetic imagination. Many other survivor poems record uninvited visitors, unwanted events, oceanic fears of time, change, and flux. Such poems perform what sociolinguistics calls an *ideational function*: they identify and categorise outer worlds beyond the self and how they are experienced.

4. coming to terms with runaway words

7. Subverbally   Joanna Watson (2009)

nevertheless
I am afraid of words
they come attached to feelings
strong when clumped together

catalysing others
gathering emotion
always more

nevertheless
I am afraid of words
not abstractions poets squander
nor flamboyant prosody
but still small words you offer
when I ask for reassurance
always more

nevertheless
I am afraid of words
for what they fail to say
when you encourage me
the undercarriage of the sky
shines down before it rains
always more

nevertheless
I am afraid of words
escorting what you really mean
beneath that shrug
behind that almost-smile
of tacit judgement
always more

8. Lessness (excerpt) *Samuel Beckett*

Ruins true refuge long last towards which so many false time out of mind. All sides endlessness earth sky as one no sound no stir. Grey face two pale blue little body heart beating only up right. Blacked out fallen open four walls over backwards true refuge issueless.

Scattered ruins same grey as the sand ash grey true refuge. Four square all light sheer white blank planes all gone from mind. Never was but grey air timeless no sound figment the passing light. No sound no stir ash grey sky mirrored earth mirrored sky. Never but this changelessness dream the passing hour.

He will curse God again as in the blessed days face to the open sky the passing deluge. Little body grey face features slit and little holes two pale blue. Blank mind.

Figment light never was but grey air timeless no sound. Blank planes touch close sheer white all gone from mind. Little body ash grey locked rigid heart beating face to endlessness. On him will rain again as in the blessed days of blue the passing cloud. Four square true refuge long last four walls over backwards no sound.

Grey sky no cloud no sound no stir earth ash grey sand. Little body same grey as the earth sky ruins only upright. Ash grey all sides earth sky as one all sides endlessness.

He will stir in the sand there will be stir in the sky the air the sand. Never but in dream the happy dream only one time to serve. Little body little block heart beating ash grey only upright. Earth sky as one all sides endlessness little body only upright. In the sand no hold one step more in the endlessness he will make it. No sound not a breath same grey all sides earth sky body ruins.

Slow black with ruin true refuge four walls over backwards no sound. Legs a single block arms fast to sides little body face to endlessness.

Never but in vanished dream the passing hour long short. Only upright little body grey smooth no relief a few holes. One step in the ruins in the sand on his back in the endlessness he will make it. Never but dream the days and nights made of dreams of other nights better days. He will live again the, space of a step it will be day and night planes sheer white eye calm long last all gone from again over him the endlessness….

Poem 7 is by a survivor-poet who took up writing after an episode of PTSD after working as a doctor in a war-zone; to me it speaks of someone haunted by language that can too often entrap and lead astray. Poem 8 is by a writer famous for his deeply melancholy disposition; to me this is an example of what Deleuze (1986) calls "making language stutter, stammer, and wail.. making it destabilise and deterritorialise the conventions of the major voice, subverting it from within"; other commentators have suggested it is a way of 'accommodating the chaos of consciousness' in linguistic form, a kind of 'dilapidation of discourse', like a deranged person or a person in a state of shock. Many survivor-poems show this feature, for example by adopting and adapting child-babble, nursery rhymes, chants, spells as devices that entrain the reader's attention and that (when scrambled and cut-up) can be profoundly unsettling. Sociolinguistics would identify this as a *textual or (inter)textual function* in which lexical play and the foregrounding of stylistic surface creates new affective assemblages or palimpsests that convey meaning through the way language is [dis]organised (through metramorphosis in matrixial borderspace?)

Working with 'mobile metaphors and meanings' as a way forward

I hope I have shown here, albeit in a preliminary and sketchy way, that the language of distress in the poetry of psychiatric survivors points to a whole new domain for study, debate and action. I'd like to end with an observation from another prominent contributor to counter-psychiatry and the mad movement (herself a clinician-researcher): "We need new accounts of the experience of mental distress, *beyond* psychiatric symptoms & diagnosis. A non-diagnostic approach is needed that attends to, describes, and tries to understand the way people's experiences of distress vary in different situations; how people's distress is fostered by very particular social contexts; the content, meanings and functions of those experiences; how people actively construct their experiences - however distressing they are**,** they may in fact be protective" (précis after Boyle). I dare to suggest that inquiry along these lines would point towards a very different 'social model'. Such inquiry is urgently needed, and it could surely help to establish a new and productive trading zone between the mad movement and the critical disability movement.

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Some thoughts towards seeking a new service paradigm in the community.

Judy Hunt

For me the focus of this seminar was: to consider the extent to which people who live as survivors of the mental health system can share common ground with physically disabled people, in terms of how society responds to their predicament, and also in their political objective for emancipation and more control of their lives through a different set of support systems.

It was, however, a seminar with a difference – by bringing together disability studies academics and students, activists from the Survivors movement and the disability movement, it generated some very interesting sharing of ideas that could ultimately lead into new practice outcomes.

Accepting the social model of disability, as the basis for analysing physical disability and appropriate responses by society towards it – we were asking if the same could be said of mental distress, i.e. was this too a socially created condition with a society's responsibility to adapt and change.

Here the arguments against accepting the concept of mental distress as necessarily either physically caused, or as an illness, were explored by a number of participants. In her paper Anne Plumb drew attention to the inappropriateness of a traditional medical service model of "care" which offers highly coercive responses to people in acute states of emotional/mental distress, rather than seeking more sensitive empathetic approaches. Locking people away in institutions and forcing behaviour changing interventions upon them cannot be a response that enables people to either manage their extreme distress or achieve a greater understanding of the underlying reasons for it. *Plumb, A. (1994)*

Both, Anne Plumb, talking about her experiences in the UK, and China Mills, of her recent researches in India, brought our attention to some of the alternative strategies people have drawn on from their communities, that demonstrate a range of possible support options for people in acute distress, that do not have to resort to powerful drugs or ECT. Talking about her experiences of India, Mills also highlighted the looming problem of exploitation by drug companies who see a new market potential in the modernising India. Populations that previously had no access to psychotropic drugs and found alternative coping strategies, often with better results, are now exposed to medications, through the use of which users in the western hemisphere are just discovering the full implications of their harmful long-term side effects. *Mills, China. (2011).*

There are two lessons here. The first is about understanding the harmful impact standard service responses can have on people in need of crisis support. The second is recognising the insights about the service problems and solutions that can arise from direct experience. Sometimes it is in the inkling of possibility, coming from people with direct experience that we find new insights into ways of providing more sensitive help.

Here I see some parallel with the lessons from the movement of physically disabled people. There too the sources of help were inappropriate, identified as disabling and dependency imposing, and the oppressive responses of a controlling body of professionals to an identified need for help. But there too, it was those with direct experience who began to identify more emancipatory ways of providing services that helped people to develop their longer term aspirations and acquire more control of their day to day lives. *Hunt, J. Unpublished*

In the 1970s-80s, disabled people sought to replace dependency service structures with enabling ones and created Centres for Integrated/Independent Living (CILs). This alternative approach itself had to build on a range of important principles.

   a) To become emancipated from dependency, people disabled by society had to engage in the process of changing it.

b) To become engaged in the process of change, disabled people had to overcome the differences that separated them and learn to work together, which was no easy process.

c) Working together meant learning the true meaning of diversity. By developing tolerance of difference, people were able to arrive at a new understanding and common objectives.

d) Through understanding difference it became possible to incorporate a wide range of experience to identify how best to solve problems of an inaccessible society.

e) Through better understanding of the reasons for their limitations it was possible for disabled people to uncover their hidden potential and identify ways to harness it.

f) This required developing new and appropriate working frameworks within which people could develop skills and capacities, and identifying the necessary skills of, and training for, a new set of support workers.

g) If social support can develop as a co-operative, power sharing, venture, between givers and receivers, it can become a mutually beneficial creative experience for both sides of the relationship.

The CILs, managed according to the original principles developed by disabled people should not be confused with independent living centres run on more traditional rehabilitation lines, nor with contemporary organisations that now adopt similar names whilst not abiding to the principle of a service under disabled people's control.

If we accept the idea that a supportive service model is one that helps people to maximise their potential to live a fulfilling and socially integrated life then we need to ask how it is to be achieved. For me, drawing on the above set of insights, this raises three basic questions, i.e.

1. What fundamental principles should we be applying?

2. What would be appropriate support capable of meeting a wide variety of human need and how will it be organised?

3. What would the process be to get there?

Looking back over time a major characteristic of service provision is of spontaneous origins and lack of planning or purposeful design. By and large, care services have been the result of charitable human reactions to identified suffering or deprivation. Once established they have grown, modified and adapted to provide responses to meet social needs but have rarely been capable of fresh thinking or radical overhaul.

In this history the deciders of what is needed and how it should be provided have largely been those doing the providing. The skill set of the workers employed to provide the different forms of care have been largely dependent on the best that was available at the time and this as it happened fell largely on the shoulders of nurses, Professions Allied to Medicine (PAMs) and Social Workers.

Now, at a time when a vacuum of service provision is likely to emerge, it is an opportunity to think again. We can ask; what have we learnt from our history and how could we initiate the development of a new service paradigm based on different principles?. Instead of a spontaneous practical response to a service gap would it not be preferable to analyse what exists, reject the bad, identify the good and plan to create something different?

In 1999, Vic Finkelstein proposed that it was now essential to develop a new specialised professional workforce who could respond appropriately to the support needs of people living in the community. These new workers, he suggested, should be referred to as the Professions Allied to the Community (PACs). It was his direct experiences of the failing care system, offered by PAMs, which he described as bankrupt, that provided the basis and justification for a fresh examination of the service relationship.

He is not the only one to complain about the existing service model. A common complaint about, and also from, professionals working in the Health system and in Social Services, has been the

erosion of their capacity for sensible decision making or scope for initiative. In replacement, we have seen the effects of formalised computerised programming of professional activity. Since these recording systems are frequently designed primarily to measure productivity and costs, one of the outcomes has been the emergence of alienating and sterile care relationships often incapable of meeting the most basic human needs.

Now, through the atomisation of services, via personalised budgets, we are rapidly moving to a situation when once again people in need of personal support, such as those who are disabled or distressed, will be reliant on a body of remote professionals determining their lives.

Before it was a problem of powerful welfare professionals making decisions on others behalf. Now it is more likely to be the problem of people being reliant on distant officials, employed by private payroll companies to manage the (rationed) personalised budgets of large numbers of people who feel unable to do it for themselves. These organisations will be remote, operating to their own rules and difficult to challenge from an individual standpoint.

Sadly, Vic Finkelstein has now died but he has, in his inimitable way, yet again offered us the seed of a new idea within which lies the potential for developing not only an emancipatory service model, but also an emancipatory process for reaching it, and it seems all the more pertinent today. As he says here;

> Community care services for disabled people based on the assessment of need and managed by PAMs demean both workers and users. They should be replaced by services based on the identification of aspirations managed by PACs in an alliance of workers and users.

> (Finkelstein, V. 1999).

What has been achieved and how did we get here is a question we need to keep asking. I think we can learn a lot of useful things from disabled people who have collectively strived to become integrated into mainstream society with proper support. I think it will be from their discoveries that we gain new insight and the seeds of a solution.

For me, it was the collaborative components of this seminar and the prospect of discovery, through co-operation between activists from different branches of the disability movement and academics, that represented the most exciting element. I hope it will be an experiment that is repeated.

Judy Hunt is a U3A Activist

A personal response

Alison Young

My name is Alison and I am not an academic, I am a student. This is in my opinion the only label I need, but I have also been told that I am schizoaffective which is a label that I try and forget, not become I am ashamed but because it does not define who I am. As can be expected I am sometimes treated differently because of this psychiatric label; so I am resistant to telling people of my 'condition'.

I have been in distress several times in my life, with spells in hospital, voluntary and involuntary, I have been arrested, locked up and forcibly treated, but I have survived and I am still surviving. The decision to come back to university is one that I have made when all around me have suggested that I take it easy, recover a bit more and generally sit on my arse and accept that I have an illness. Just because you have an illness does not mean you have to give in or give up or even be defined by the labels that are attached to you as person and as a group in society.

My university life has been a rocky one, I have taken six years to get to my third year as a Criminology student and I would not be here if it were for the support I receive and I still receive. I have been and I am still scared I will not be accepted like any other student but over the last couple of days I have felt that I belonged, this is something I have wanted to feel all my academic life and at Lancaster University I do fit in.

The symposium I have just attended, 'Distress or Disability' was one that I had asked to be invited too, never imagining that little old me would get an invite, but I did. When I walked through the door the first person I saw asked whether I wanted a cup of coffee. I was apprehensive of saying yes as my hands shake because of the Lithium I take, and I imagined most of the coffee would end up on the floor. So he kindly took me in to the conference hall and sat me down, with the coffee in one hand and my gratefulness in the other. The other delegates around the table introduced themselves and I was immediately struck by the diversity of the group I was with. We didn't know what to expect, even though nearly all of them had been at other meetings like this before. I was not left out of the discussions after some of the papers were presented even though some of the topics were slightly over the top of my head, but I learnt.

I have learnt over the last couple of days that most people have had difficulties in their life, some that define who you are and make you a 'better' person and other difficulties that are harder to learn from.

I know the content of the symposium was perhaps not about reflection but to me, that is what it is mainly about. I reflected on who I was and who I am now, this has been a life changing experience for me and one I will never forget. I was made to feel included, understood and accepted for who I was and this was not schizoaffective, but rather a student who has positive possibilities in life.

I want to tell you of an incident that happened on the Tuesday of the symposium. We were having a discussion around the table about one of the papers that had been presented; I was trying to keep up and look like I knew what the other delegates where talking about, where I was struggling a bit. A lull in the conversation gave me the opportunity to make an impromptu statement. I said that I felt a fraud because they, the delegates and the ones presenting the papers, were talking about people like me. The delegate across the table from me made a remark that I will not forget, he said, 'how do you not know we are not all like you?' Well that struck me as quite prophetic and it made me think that perhaps we are all a bit scared of things in life and this could make any one of us ill.

This is a big thank you to all who organised this symposium and I might have not written about the content of the papers, but for me it was just as important to express how being a participant felt. And next time I spill a cup of coffee because of my incessant shaking I will remember not only the lovely guy who offered his assistance but also the friendly faces of my fellow delegates and I am proud to say I was one of them.

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