



Start Making Sense...
Developing social models
to understand and work with
mental distress

Notes from SPN study day 11 November 2002

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Contents

<i>Foreword – what the study day was about</i>	Jerry Tew	1
<i>Core themes for social models of mental distress</i>	Jerry Tew	3
<i>User perspectives and user knowledge – some headings</i>	Peter Beresford	5
<i>The social/trauma model: the mental health consequences of childhood sexual abuse and other life events</i>	Sally Plumb	6
<i>Finding a way forward: a Black perspective on social model approaches to mental health services</i>	Peter Ferns	16
<i>What is recovery?</i>	Jan Wallcraft	25
<i>Women: a social inequalities perspective</i>	Jennie Williams	27
<i>Lesbian and gay perspectives on mental distress</i>	Sarah Carr	33

www.spn.org.uk info@spn.org.uk

Foreword – what the study day was about

By its very nature, mental distress may be a profoundly confusing and frightening experience, both for those going through it and for those close to them within their social and professional networks. Part of the attraction of the biomedical model has been that it seems to provide answers, meanings and certainties. However, for many people, it does not always provide the most helpful ‘pegs’ on to which to hang their experience.

The aim of the study day was to bring together a range of social perspectives that may be useful in understanding mental distress and the social and personal issues that may connect with it — concepts and models that may help to move us beyond the territory of just treating symptoms, and provide frameworks that may be useful in giving meaning to experience, and in enabling and supporting recovery.

Presenters brought with them a broad diversity of experience, including service user, practitioner, trainer and academic backgrounds. It was intended that the day should be inclusive of a range of perspectives that particularly reflected the experience of those service users, allies and professionals whose voices may often have been marginalised on the basis of their ‘race’, gender, sexual orientation, status or other factors.

The day was deliberately set up as a ‘melting pot’ of ideas. Each presenter was given the brief of introducing some of the key ideas that they saw as crucial in making sense of mental distress and in guiding how best to respond to and work with such experiences. The presentations were marked by a refreshing degree of honesty and directness — a willingness to take the risk of speaking from potentially very painful personal knowledge, and to raise issues of injustice in all their stark reality.

There was a commitment to share within the spirit of dialogue, rather than discussion — that is to say, an expectation that we would not simply reiterate established positions and understandings, and bat these back and forth, but that we would encounter new ideas with an open mind, hoping to learn from and be moved by them.

During the course of the day, participants were invited to try out the various concepts and perspectives that had been presented in order to see how they fitted with their own personal and/or practitioner experience. Following on from this, they were asked to explore what common themes seemed to run through the diverse perspectives that had been presented. Out of this, it is hoped that we may become clearer as to what may constitute the ‘core’ of all social perspectives.

As may be seen from the notes from the working groups, key themes that were seen as underpinning all social perspectives included an understanding that mental distress can be linked to issues of powerlessness, inequality, oppression and loss. However, service users must not be seen as passive victims of social processes, but as people who are actively grappling with complex issues of identity

and meaning and with problems of daily living, within the constraints and opportunities of their particular social contexts.

Mental distress must be seen as situated within a continuum of lived experience — there is no room for ‘us’ and ‘them’ thinking that can divide service users from carers or practitioners.

A second task for the working groups was to identify any significant gaps or areas of potential tension and conflict between the different perspectives that were presented. Out of this it might be possible to identify some of the most important areas for further work in terms of developing theories and approaches to mental distress.

Interestingly, as may be seen from the notes from the working groups, there was a general view that, as long as the development of social perspectives did not lead to the construction of a one-size-fits-all social model that professionals could impose on people – an approach that could be as oppressive as the medical model itself – then there were not any important areas of potential conflict between the different sets of concepts and ideas that had been presented. The day had much more of a ‘both... and...’ feel, rather than a set of ‘either/or’ dichotomies.

And it produced an interesting shopping list of areas for further work that will need to be taken up in subsequent SPN study days.

What follows are the notes that have been made available by the individual presenters, followed by the notes from the working groups. Work is under way to use extended versions of these presentations, together with some additional invited papers, as the basis for a book to be published by Jessica Kingsley. It is hoped that we will be able to have this finished later in 2003.

Jerry Tew

University of Central England

Publisher’s Note

The Social Perspectives Network for Modern Mental Health (SPN) has been hosted since its launch in February 2002 by Topss England, the strategic body for workforce development in social care. This is the third SPN paper to be published under those auspices. However, as this paper is being prepared in early 2003, work is also underway to transfer the hosting of SPN to the Social Care Institute for Excellence (SCIE). Topss England is very pleased to be associated with SPN, and is confident that a close relationship will continue as work on developing the mental health workforce proceeds, and as the partnership between SCIE and Topss England leads to an increasingly mature relationship between research and workforce development.

Core themes for social models of mental distress

Jerry Tew, University of Central England

Research based on longitudinal surveys shows that advances in pharmacology and other medical treatments have resulted in little consistent improvement in recovery rates—so we cannot say that the medical model, on its own, is a sufficient basis to underpin policy and practice in mental health. Instead, variables such as cultural setting and unemployment rates appear to have a much greater impact, and there is some evidence that socially oriented services may achieve higher recovery rates. (Tew, 2002)

Through a range of networks, dialogues and explorations, some elements of a radical consensus are beginning to emerge—a consensus that links the voices of users, and their families, friends and allies, with those of certain practitioners and academics from across the full spectrum of mental health disciplines. This consensus suggests that, while medical technologies may make a valuable contribution in enabling people to manage specific vulnerabilities and reactions to stress more effectively, mental health promotion, crisis resolution and longer term action to support recovery may need to be underpinned more explicitly by social perspectives.

What has *not* so far happened is for the various strands of alternative ‘social’ thinking (which have emerged somewhat in the shadow of the medical model) to be brought together as a coherent model, or set of perspectives, in its own right—one that can, in its own way, be as influential on policy and practice as is the medical model.

The need for a more holistic approach is reflected in the National Service Framework for Mental Health, in which concepts such as social inclusion and recovery play an important role. This also recognises that a broader evidence base is required than that provided by evaluations of medical treatments. In turn, this agenda is now being taken forward by, among others, the National Institute for Mental Health in England and the Social Care Institute for Excellence.

However, although there may be a groundswell of interest in social perspectives, there is currently a lack of clarity as to what exactly is meant by a social model of mental health (if indeed it is a singular model that is required at all), and how such approaches could be more effectively implemented in practice.

I would argue that at the core of a social model are two parallel perspectives that link ‘mental distress’ with ‘problems of living’:

- In one sense, mental distress may be seen as a reaction to a range of social circumstances and relationships (past and present) that may be experienced as painful, contradictory, unjust, excluding or oppressive, and where no other avenue for resolution appears to present itself. In this sense, it may often link with issues of powerlessness and loss.
- In another sense, what may be seen as the manifestations of mental distress, such as voice hearing or self harming, may also be understood as the best available set of coping or survival strategies that a person may be able to access, given their particular history and

social circumstances. In this sense, distress may paradoxically be seen as a reflection of people's resourcefulness and ingenuity.

Thus, at one and the same time, mental distress may constitute both an awesome story of survival in relation to oppressive or 'unliveable' situations, and a desperate cry for help and understanding. Whether viewed as a coping strategy or as an expression of extreme disquiet, it may represent a way of being that is lived out at some considerable cost to the person, and may potentially pose difficulties or risks both to them and to those around.

There is nothing new about social perspectives. In different ways, understanding the interrelation of 'mental distress' and 'problems of living' is something that has, for many years, been on the agenda of, among others:

Social psychiatry

- Identifying stressors in family and community living, e.g. expressed emotion – although drawing short of seeing these as potentially contributing to initial breakdown
- Importance of work and meaningful activity

Psychology and psychotherapy

- Links between personal trauma and distress, e.g. sexual abuse

Sociology

- Impact of poverty, discrimination and social exclusion on incidence of mental distress
- Concepts of social capital, social structure, systems, etc
- Deviance, labelling theory and stigmatisation

Social work

- Practice based on awareness of power issues—value base of anti-oppressive practice and empowerment / partnership
- Focus on needs rather than diagnoses / classifications

Transcultural psychiatry / anti-racist perspectives

- How problems of living and mental distress may be expressed and dealt with differently in different cultural contexts
- Service responses often determined by stereotyping e.g. big, Black and dangerous
- Need for holistic assessment, e.g. Letting Through Light initiative

Women's movement; lesbian and gay perspectives

- How oppression and conventional social roles may link with particular mental health issues for women and men, lesbians and gay men
- History of psychiatry buying into oppressive stereotypes in relation to gender / sexuality

Disability movement

- Social model of disability: it is society's (and professionals') responses to impairments, rather than the impairment itself, that can be most disabling.

Service users

- Lived experience as a primary basis for knowledge and understanding
- Professionals do not listen to the whole of people's experience, including the 'mad' bits
- Understanding 'symptoms' as survival mechanisms
- Social issues, e.g. poverty, isolation, lack of employment, housing, can be more of a priority day-to-day than managing psychiatric symptoms – and resolving

social issues can, in turn, make it much easier to live with psychiatric symptoms

- Mad Pride – assertion of ‘difference’ as a positive identity

Allies, relatives and friends

- Mental distress may be reflected in disrupted or challenging relationships
- Tendency for services to individualise problems and exclude friends and relatives
- Those in connection with a person in mental distress have support needs of their own

Recovery movement

- Recovery depends on finding a way of understanding and giving meaning to experience that enables a person to reclaim control of what is going on for them
- Recovery is about claiming / reclaiming a socially valued lifestyle, and social empowerment, rather than becoming ‘symptom-free’.

This list is by no means exhaustive, and only a small proportion of what is contained here can be examined more fully in today’s presentations.

Reference

Tew, J. (2002) Going Social: Championing a holistic model of mental distress within professional education.
Social Work Education 21:2

Jerry.Tew@uce.ac.uk

As the range of this material unfolds, a number of issues emerge. While there may be important areas of consensus, there may also be crucial areas of contradiction and difference. It is important that we approach this in the spirit of dialogue rather than discussion, to use Peter Senge’s distinction – a willingness and expectation that we will be moved by what we hear and encounter, rather than engaging in an exchange of views from entrenched positions. However, we must also be aware of ever-present issues of inequality and power, how some voices have tended to be heard more than others. Whose views and experiences will be privileged in deciding what is important in a social model?

Finally, we must remain open-minded and critical about the pros and cons of having a ‘social model’ (or models) at all, balancing the need for a reasonably simple and coherent framework in order to underpin practice (or else we are left just with the medical model as the only framework) against the danger of reducing complexity of peoples lives into a neat formula that mirrors the reductionist tendencies of the medical model.



User perspectives and user knowledge – some headings

Peter Beresford, Brunel University and Open Services Project

- What do we mean by inclusion?
- The obstacles in the way of service user involvement
- Traditional approaches to ‘social perspectives’
- Service users and the difficulties of breaking out of dominant thinking
- Service users’ social approaches
- Mental health service users’ explorations for the future
- Indications and implications for the future
- Next steps.

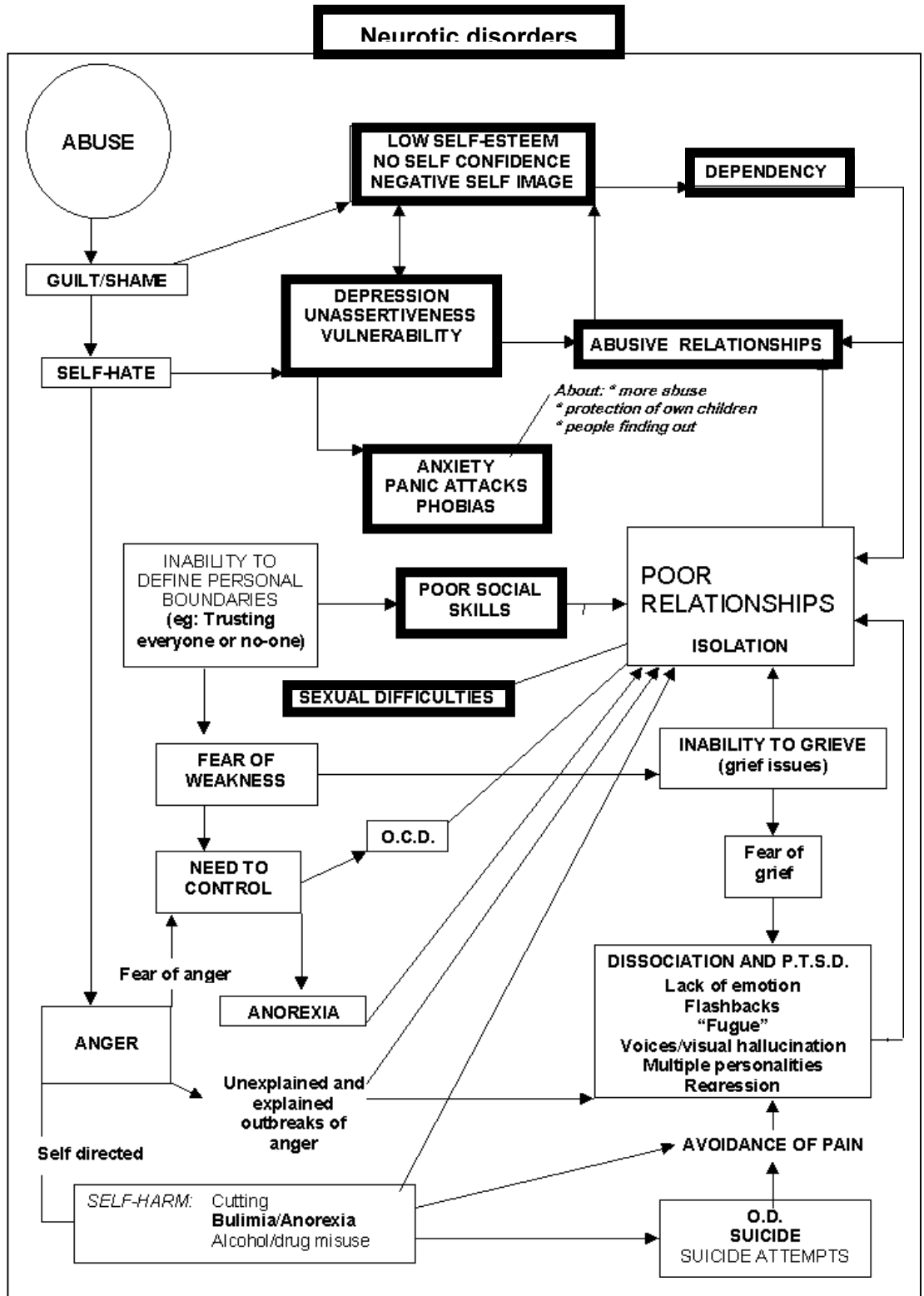
SPN has commissioned Peter to write a paper in 2003 to expand this important discussion of user perspectives.

their personal qualities, support structures, type and duration of abuse, relationship with the abuser, response to disclosure, degree of threat used in coercion and the cultural, gender and class contexts which define the individual.

These connections are a result of my experience as a specialist mental health social worker and are therefore my opinion and not the result of research or experiment. However, I have shared them both with other people working in this field and with abuse survivors and they have generally felt that they reflect their experiences.

The diagram is a simplification of a complex set of inter-relationships. It is not comprehensive; if it was it would be impossible to decipher.

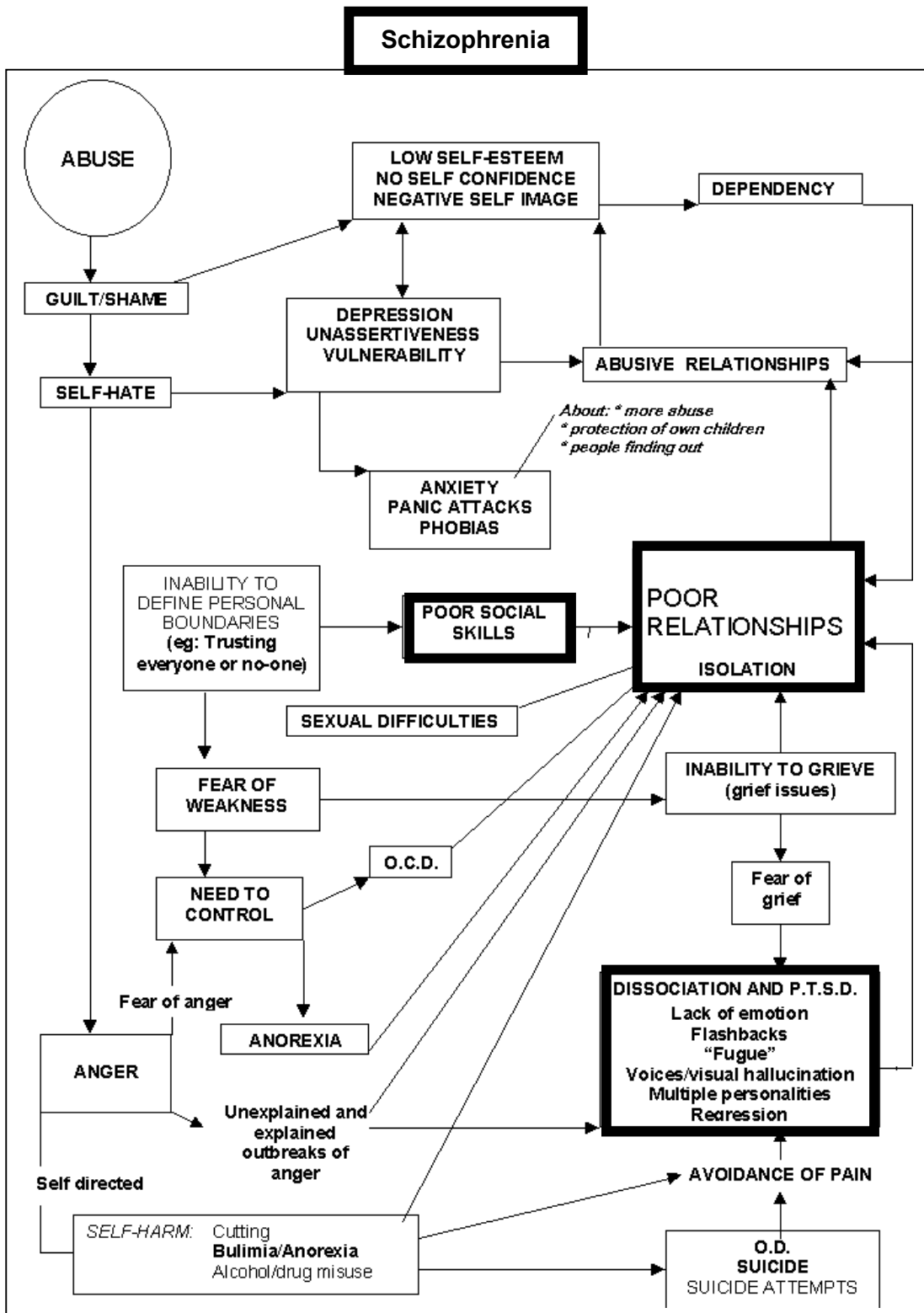
Written across all of this could be, in large red letters, the word FEAR.



protect oneself causes feelings of helplessness. Hopelessness and helplessness are key feelings in depression.

Anger

Anger at abuse and the betrayal of trust is a valid response. Anger can also be a positive energy for change. However, turned inwards it can be very damaging. Behaviours such as cutting, bulimia (and to an extent anorexia), alcohol and substance misuse are all ways of being angry with oneself. Outwardly directed anger can also be problematic when it is inappropriately directed or appears unexplained. High levels of apparently unexplained anger can attract psychiatric labels such as mania and personality disorder. It can also lead to legal difficulties and a criminal record.



Inability to trust – boundary difficulties

One of the main features of abuse by an adult or close relative is that it is a betrayal of trust. It undermines any sense that other people, or oneself, can be trusted. This leaves feelings of anxiety and vulnerability.

of which are logical and appropriate results of being abused. One of the causes of anorexia is a need to control food intake and body weight because of a feeling of being unable to control anything else.

Anxiety

Feeling vulnerable and unable to protect oneself, feeling there is no one who can be trusted, being in a situation where physical or sexual abuse are still happening are all causes of anxiety. Worry about being hurt or abused again, that your own children may be abused (or even that you may abuse your own children) and, particularly, worrying about people finding out that you have been abused all create a constantly heightened level of anxiety. Panic attacks and phobias are both results of high anxiety levels.

Sexual difficulties

It is not surprising that first experiencing sexual activity as frightening, coercive, confusing, shrouded in secrecy and often painful and physically harmful does not create a sense of sexuality and its expression being desirable, mutual, pleasurable or even safe.

Many survivors' sexual pleasure in adult life is also blocked by learned techniques of emotional and sensual withdrawal. Choosing not to experience sexuality either with the self or other is one way of dealing with this. However, feelings of vulnerability and dependency can leave survivors feeling unable to remain outside romantic relationships and thus often unable to withdraw entirely from sexual activity.

Feeling a lack of free choice in expression of sexuality, either through a sense of duty or through overt coercion from the partner, is an echo of the coercion and helplessness present in the first abusive experiences. Even

with a sensitive and consciously non-coercive partner, the feelings, sights, smells, sounds and fact of sexual activity can all recall the abusive experiences and result in either withdrawal, distancing or 'flashbacks'.

Withdrawal from sexuality is one response. Confusion between sex and love, a sense of being already 'used goods' and unclear sexual boundaries can all lead to unsatisfying sexual experiences that it may not be possible to limit. Many children who are sexually abused receive sex when what they are hungry for is love and positive attention. If the abuse is accompanied by rewards in either money or kind, it can result in sexual activity being seen as both a tool and a weapon. In adult life the search for a sense of worth and being loved, as well as a need to protect oneself or to survive economically, can all lead to sexual activity which is not mutual, pleasurable and chosen activity.

Avoidance of pain (dissociation)

The original abusive experiences were painful, both emotionally and usually physically. The feelings of guilt, anger, self-hate and shame are still painful.

At the time of the abuse many survivors coped by withdrawing, or dissociating themselves from the pain. This is done by either believing that what is happening is happening to someone else, or that the person is actually not there at all. Survivors have been able to achieve extraordinary abilities to not experience pain and at the time this is a functional and very effective defence. One survivor has described to me how she had an imaginary friend who was the one who experienced the pain and fear, not her. Many abusers threaten their victims in case they tell someone about what is happening to them, or express their anger about their experiences.

Thus anger or telling become unacceptable. The abuser may also tell the victim that they are bad, wicked, dirty and in order to survive such self-destructive beliefs they may also be compartmentalised. Such habitual separation of feelings and urges from the 'self' as consciously experienced can mean that they are experienced as 'other', outside the self and perceived as voices. They can also be experienced as 'multiple personality disorder'. Another survivor has described how she can feel and express anger when operating as a different self, with a different name, which dresses and behaves differently.

Repressed or extremely painful memories may only be experienced as 'flashbacks', sometimes accompanied by the voice and behaviour regressing to the time of the memory.

The survivor is, as far as they are concerned, actively re-living the event and sounds and sights of that time seem really present. To anyone observing this process the voices and sights are not real, i.e. they are hallucinatory.

Experiencing flashbacks and memories can intrude into a survivors' current attention—they 'tune out' and lose the ability to concentrate.

Habitual emotional withdrawal as described in the section about sexual difficulties can produce an inability to connect with emotions and feelings. This can be seen as an emotional flatness.

Post Traumatic Stress (Disorder) [PTSD] can reflect many of the effects of dissociation, and indeed dissociation is the dynamic leading to much of this range of effects of trauma.

Avoidance of pain (self-harm)

Abuse survivors feel current pain. This is made up of memories of pain, pain at negative feelings and pain at the difficulties of living with all the consequences of the abuse. Many survival techniques useful and appropriate at the time of the abuse may now be destructive and dysfunctional and cause current pain.

Pain can be avoided in many ways, either by blocking it by use of alcohol and prescribed and illegal drugs or by substituting a more controlled and physical pain. Physical self-harm such as cutting, burning or other self-inflicted injury brings genuine relief, albeit temporary, from emotional pain, because it is in the control of the survivor and the emotional pain is not. The bingeing, vomiting and laxative abuse behaviour in bulimia bring the same relief.

Abuse of alcohol can have an additional 'benefit' for survivors as it can help to access memories and feelings otherwise not accessible. Alcohol, prescribed and illegal drugs can also be experienced as very helpful in getting to sleep and in preventing distressing and frightening dreams.

Unfortunately, all these pain-avoiding techniques have their own attendant difficulties. They add to the feelings of self-hate and disgust. They also block the healing process of experiencing and resolving the feelings resulting from the abuse.

For many survivors the pain, helplessness and hopelessness are too much to bear and the ultimate pain avoidance is death. Urges to take overdoses or commit suicide are often very strong and can be ever-present.

Poor relationships and isolation

It is no coincidence that ultimately all the arrows seem to lead back to the box marked 'poor relationships/isolation'.

Feeling guilty and anxious about people finding out about the abuse makes it feel safer to avoid close friendships and relationships. Feeling unworthy, dirty and unlovable makes relationships seem inappropriate. Experiences of being abused, particularly when accompanied by learning that no one can be trusted, feeling vulnerable, unassertive and unable to protect oneself makes relationships seem dangerous, although sometimes apparently necessary. Sexual difficulties can lead to avoidance of sexual and romantic relationships, as can guilt about previous inappropriate sexual behaviour. Outbursts of anger, particularly if inappropriately directed, or emotional flatness all militate against good relationships. The guilt and shame attached to self-harming behaviours makes relationships seem difficult. Insecure sexual boundaries and poorly developed response to the need to feel in control can all cause problems. Additionally, the stigma attached to mental illness can exacerbate these problems if the consequences of the abuse have resulted in a psychiatric history.

Potential for psychiatric misdiagnosis

As can be seen from the diagram of the social/trauma model, many of the difficulties experienced as a result of abuse, trauma and oppression can either *be* mental health problems, such as depression or anorexia, or could be *mistaken for* mental health problems such as schizophrenia (hearing voices, seeing things and/or emotional flattening), manic depressive illness (outbursts of anger, agitation, depression and changing emotional states) or personality disorder, particularly borderline personality disorder (self-harm,

overdoses, emotional instability, impulsiveness). Research is beginning to demonstrate high percentages of people with diagnoses of serious mental illnesses who have histories of childhood sexual abuse. However, the logical, rational and necessary consequences of that abuse may not be those illnesses themselves but can be mistaken for them. I believe that this is becoming increasingly apparent.

Abuse, trauma and oppression – links with multiple needs and homelessness

People who have experienced abuse, trauma and oppression and who are surviving and coping within the social/trauma model are very likely to fit the description of 'multiple needs'. How these arise, and their relationship with adverse life events, are demonstrated by the social/trauma model. One of the ways that people cope with abuse and oppression is by escaping, often leading to homelessness due to a lack of alternative safe places. The difficulties that they experience as a result of their abuse can also lead to homelessness. Many of these difficulties can make them hard people to help and they often fall outside the boundaries set for particular services, such as self-harm, psychiatric diagnosis, suicidal feelings and difficulties in engaging. They may find it very hard to trust people and have poor social skills and boundaries.

Implications for helping services

The main effects of abuse and oppression are damaged boundaries and powerlessness. This has implications for how services are provided. They need to be empowering and have good, appropriate boundaries. They also need to understand that people's difficulties are their most effective ways of coping with their experiences, given their circumstances, and these need to be respected and

accepted, not judged or punished. You cannot expect people to give up the ways that they cope unless they can find 'better' ways and/or a less abusive environment.

It is essential that services do not replicate the abuse. They need to be safe, accepting, empowering, nurturing, containing and appropriately structured. Negotiation rather than coercion are essential. They also need not to be conditional in their acceptance, while retaining boundaries. People who have been abused and oppressed are often desperate to please, believing that it is their own unacceptability that has caused the abuse, and they need to be encouraged to make choices for their own benefit rather than to please others.

Because of the potential for psychiatric misdiagnosis, it is essential to keep an open mind in the face of such diagnoses and not to view people through the lens which defines people by their diagnosis.

Implications for disclosure

For most abuse survivors, disclosing is a very difficult and frightening process, no matter how desperately they feel the need to do so. Difficulties in knowing who they can trust, fear that their disclosure will be met with disbelief, blame and punishment, and the threats against disclosure possibly made by their abusers, are all barriers. The gender, cultural background, status and position of the person they are considering disclosing to will also help or hinder this process. They can also fear the impact of their information on the hearer, wanting to protect them from the shocking, shameful, unbelievable and 'contaminating' contents. Feeling disempowered and with damaged boundaries, the survivor can only achieve sufficient safety to disclose if they are offered

appropriate boundaries (including explicit boundaries on confidentiality) and are empowered by the interaction.

Implications for helpers

Trying to help someone who has been abused and/or oppressed and who is cycling around in the social/trauma model can feel very much like being in that model yourself. The traumatic content of their experiences can traumatise those they talk to about them, their damaged boundaries can disrupt the helper's boundaries, coping through chaos can spread chaos and their sense of hurt and helplessness can make the helper feel powerless and inadequate. Repeated crises, suicidal feelings and actions, high levels of distress and despair can stress and distress those around them and trying to help them. As a result, helpers and supporters risk experiencing the effects of the social/trauma model and it is essential that they are given adequate support, boundaries and supervision as well as encouragement and permission to look after themselves.

Those helpers who have themselves experienced abuse, trauma and oppression in their own lives (as many people have) are very vulnerable to having those experiences reactivated. This does not mean that they should not do this work, indeed they often have rich resources and understandings to bring to it, but that they need to have achieved a level of understanding and resolution and will require the best levels of support and supervision, as well as an ability to be honest with themselves and their supervisor about their experiences, so they can be appropriately supported.

Dissociation

When experiences are split off and compartmentalised, it tends to be along the following lines:

B – behaviour

Disconnected and not congruent to the situation

A – affect (feelings)

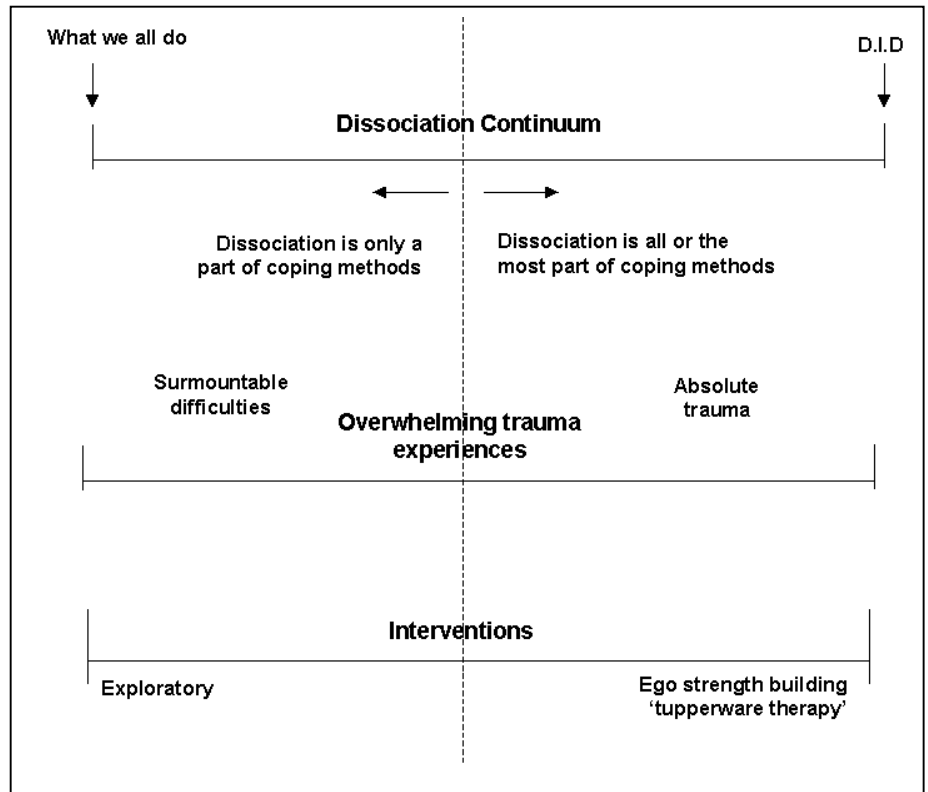
Split off and not experienced or recalled

S – soma or sensation

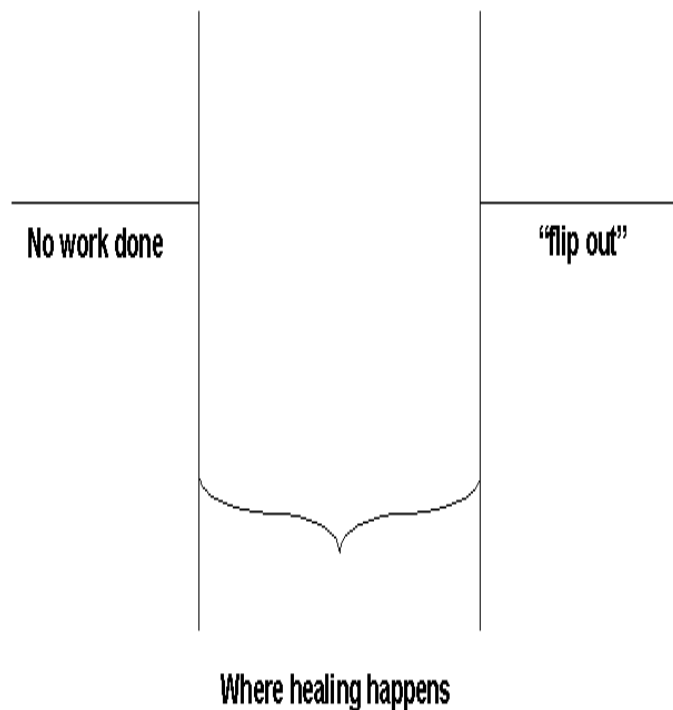
Disconnecting the pain or physical feeling

K – knowledge

Not ‘knowing’ about the events or their implications



The therapeutic window – from Brière



- This may be very narrow as the person operates further up the continuum

- Intervention aims to increase the width

The office manager – flashbacks

Normally, memory is stored in a processed form. Under situations of high arousal (e.g. fear, horror, trauma) the processing is missed out and the memories are stored unprocessed, as if they were a video.

It is like an office. The experiences are the incoming post. Normally, memory (the admin worker) will open the post, date stamp it and file it or put it into pigeonholes. Thus the material (the post) is stored in a processed form (normal memories). However, if the admin worker is very stressed (in high arousal) they can't cope with the incoming post so they put it in a box and store it under the desk, in an unprocessed form. The office manager (the psyche, or internal psychological processes) comes along and says "we can't have this" and puts the box of post back into the "incoming post" tray.

These are flashbacks. They come back unprocessed, like a video, with all their attendant feelings. If the admin worker has rested and is feeling better, they can process the post as they would have liked to in the first place. If, however, the admin worker is still stressed and upset by the re-appearance of the post, they "flip out" again and put it back in the box under the desk. The office manager comes along again and puts the post back in the "incoming post" tray.

This will go round and round until either the admin worker feels strong enough to deal with the content of the post, or has become 'desensitised' to it.

Finding a way forward – a Black perspective on social model approaches to mental health services

Peter Ferns

Introduction

Black service users and practitioners welcome the current debate about the centrality of a social model in modern mental health services. However, there is a fear that once again the Black perspective will be an ‘add on’ feature to some other mainstream theory, as in many of the recent initiatives and innovations in the development of new approaches to coping with mental distress. We believe that equality and diversity are an inherent part of good practice in mental health services in our society. No new model of mental health service delivery, ‘social’ or otherwise, should be proposed without a thorough analysis of how it relates to issues of equality and diversity and how it actively promotes these outcomes. This brief paper is an attempt to raise some fundamental issues that need to be covered in the formulation of any social model of mental health that aims to address the specific issues for Black and ethnic minority people in need of mental health services. We have a valuable opportunity to move service development in a different direction and this paper aims to contribute to finding a way forward.

The term ‘Black’ is used here in its political sense to denote people who are visibly different in appearance from the White population and are thereby vulnerable to White racism. The term recognises and acknowledges that White ethnic groups also face discrimination on the basis of culture, language, dialect and religion — issues which form part of an overarching concept of racism. Although the experience of White racism is different for Black people, the discrimination faced by some White ethnic groups is no less

important or serious. We need only look to the new ‘demonisation’ of asylum seekers and refugees, Black and White, in this and many other countries. If racism is to be defeated in our society, Black and White people must stand together and work across all ethnic groups for social justice and equality.

This paper comments on the current context of Black peoples’ experiences of mental health services and make some links to a common past for Black people that continues to inform and shape our experiences in this society. It will set out some key prerequisites for any new social model of services that is to incorporate a Black perspective of mental health. Finally, it will outline a few challenges for mental health services in the future if they are to address the concerns of Black service users. Much of the thinking in this paper has been shaped by some recent research I and others have undertaken with Black service users in Birmingham. They have crystallised many ideas through their constant questioning and challenging which I have found invaluable. I thank them for their generosity in giving their time, energy and honest views during the research.

Context for Black service users

Black experience of mental health

Control

Black experience of mental health services has been one more of ‘control’ rather than ‘assistance’ to overcome mental distress. The experience of social control has resulted in avoidance of mental health services especially by young Black people in mental distress. Avoidance then leads to crises which often

result in the involvement of the criminal justice system, thereby increasing the sense of being controlled rather than being helped (see *Circles of Fear*, 2002, The Sainsbury Centre).

Stereotyping

Decisions about dangerousness and risk assessments are still being based on stereotypical views of Black people. Broader stereotypes such as Asian families 'looking after their own', Black people being inarticulate or assuming that Muslim communities do not have alcohol or drug problems result in serious shortages of appropriate services for communities in need.

Intellectual superiority

People who do not have English as their first language are often assumed to be unintelligent. If their culture is misunderstood or not valued their cultural preferences may be seen as inferior to the norms of the dominant culture. It becomes more likely that practitioners with such assumptions will make decisions 'in the person's best interests' without involving them. The person on the receiving end of such decisions will inevitably experience them as being patronising.

Undermining autonomy

Lack of involvement in decision-making increases the dependence of people and reduces their autonomy. The lack of participation of Black service users in service delivery and development, even at times when they are not in distress, further emphasises a negative image of Black service users as being inarticulate, submissive or untrustworthy.

Divide and rule

Over-emphasis on diagnosis leads to false assumptions that people have very different needs and feeds fears arising from stereotypes about diagnostic labels. Black service users

are not facilitated to create a sense of solidarity among themselves or to build networks of mutual support where possible. In some localities differential levels of mental health services have developed for specific ethnic groups. This has led to tensions between various ethnic groups as they compete for scarce resources.

Cultural suppression

Black and ethnic minority service users are given subtle (and sometimes not so subtle) messages that their cultural identity is a problem for services. They are constantly being told that their needs require 'extra resources' and so cannot be met at that time. For example, something as basic as food on a psychiatric ward can be designated as a 'special diet' for a person from a different culture. It is no wonder that many Black service users play down their cultural differences for fear of not getting a service at all.

Punishment

Services often set out clear rules for people to be able to use the service, which may seem perfectly logical to practitioners but maybe be mystifying or unnecessarily restrictive for Black service users. If rules are broken, service users often feel that they are 'punished' for stepping out of line, particularly in ward settings. For example, if service users are unhappy about their medication it is immediately framed as 'non-compliance'. Given that Black service users are more likely to receive higher dosages of drugs, they are more likely to be seen as being non-compliant and thus problematic for services.

Demonisation

Black men in mental distress are acutely aware of media images of dangerousness and violence that are associated with them. Men who are big or tall particularly feel that they are

feared rather than approached with genuine concern for their distress. Even within their own communities Black service users may experience rejection and distrust as these communities are also influenced by negative media images.

Slavery and colonialism revisited

The Black experience of mental health services has a familiar feel to it, not least because it is a part of a legacy from the past. Deep in the psyche of Black people in this country there is a vaguely remembered experience of slavery and colonialism. These are, after all, what brought many Black families to this country in the past. There are constant almost imperceptible reminders of that past for many Black people here, even those born in this country. It is difficult to put your finger on it unless you go to ports like Liverpool, Bristol or London where remnants of that legacy still have a direct impact today. It may be argued that such old history has no relevance to young Black people born here, but there are some striking echoes of slavery and colonialism in the current experiences of Black people in mental health services.

For instance, *control* was a key feature of colonialism and a great deal of effort was made to gain and maintain social, economic and political control of colonised countries. *Stereotyping* was used to justify a level of control and exploitation of certain countries with indigenous peoples being portrayed as 'primitive' or 'savage'. In ex-colonial countries this process still continues. A few years ago, in Australia, the One Nation party maintained that Aboriginal people used to 'eat their children'. They managed to win a significant proportion of the vote in local and general elections.

One of the most damaging negative views of Black people was that they were intellectually

inferior to White people. The assumption of *intellectual superiority* still emerges regularly in service delivery when cultural differences arise in mental health, child-care and family lifestyles. It was common for colonisers to actively *undermine the autonomy* of indigenous peoples, at first by military means and later by more subtle methods of political manoeuvring and economic dependence. It is cogently argued that the activities of the World Bank and the International Monetary Fund along with globalisation add up to a neo-colonialism by the West that increases domination by consent in developing countries as they pursue the promise of Western wealth.

One of the most effective methods of control was the *divide and rule* approach. Through the exploitation of differences between people the cohesion of a country can be prevented, making it easier to dominate as no concerted opposition emerges. The disastrous and tragic results of such a policy were most clearly seen in Rwanda where the former colonisers exploited differences between Tutsi and Hutu people.

Cultural suppression was another means of total control by colonisers, particularly in restricting use of indigenous languages and artistic expression whilst vigorously promoting a dominant White culture. Aboriginal people in Australia refer to this process as 'cultural genocide'. Any resistance to domination resulted in severe *punishment* for the ringleaders variously described as 'terrorists' or 'freedom fighters' according to the perspective taken. The final and most potent propaganda weapon by colonisers was the *demonisation* of certain individuals or groups as being 'evil', 'barbaric', unpredictable and 'out of control'. This approach enabled colonial authorities to do whatever they wanted to deal with such individuals or groups.

It should be no surprise that there are these links between Black experiences of mental health services, slavery and colonialism. The mechanisms of oppression do not change over time because they continue to be effective. As these mechanisms become more embedded into the fabric of institutions they become harder to detect and challenge, thereby increasing their effectiveness. Australian Aboriginal people talk about 'death by welfare' where social control is disguised as concern for welfare of the community and state benefits are used as a means of subjugation and of breaking the traditional spirit of communities. We must never forget that the 'path to hell is often paved with good intentions'.

The oppression equation

It is worth defining some fundamental concepts before applying them to the way in which mental health services operate for Black people. Institutional racism is just one aspect of a wider problem of oppression for a variety of groups of people in our society. The abuse of power is at the heart of oppression and it will be argued that power has no place in professional practice in mental health services. People who are perceived as being different in society are vulnerable to stereotyping through the aggregation of individual prejudices of people over time. So once stereotyping affects people who hold power in society, negative values are ascribed to certain groups.

The values ascribed by stereotyping influence the culture of communities and organisations and shape certain behaviours of the individuals concerned. The result of this process is discriminatory behaviour by individuals as well as institutional discrimination. An oppressive culture begins to create organisational systems and policies that are inherently and covertly discriminatory and which in turn drive even more discriminatory behaviours of individuals.

We can summarise the process with the following 'equation':

Power + Stereotyping => (-) Values

The quick fix

A major problem for all service users is the addiction of many practitioners to the 'quick fix' in mental health service delivery. This is the tendency to focus only on the use of medication. Black service users are particularly prone to being subjected to the quick fix as practitioners often see their needs as being more complex and overlaid with issues of transcultural work. Where there is a greater lack of understanding due to cultural differences about mental distress, it is more likely that practitioners will resort to physical or drug treatments.

The drawback about the quick fix is that it often leads to longer-term problems as the real causes of distress are not tackled. The social, economic and environmental causes of mental distress are ignored through a narrow medical approach. In particular, a chemical solution takes away any responsibility from the mental health system or society at large. People are conveniently relegated to a minor role in the situation and intervention becomes a technical problem to be solved. Furthermore, it takes away responsibility from the person in mental distress as well. It is not surprising that the quick fix becomes such an attractive proposition for all concerned. We have to cure our addiction to the quick fix and take a more holistic approach to tackling mental distress. It may be harder and more complex but in the long run it is much more effective.

Prerequisites for a social model of mental health from a Black perspective

It is not the intention in this paper to set out a blueprint for a specific social model that is appropriate for Black people. There are many

possible social models of mental health but if they are to incorporate a Black perspective any social model must address the following issues:

- power and authority
- equality and diversity
- organisational change
- professionalism
- participation.

Power and authority

Power can be defined as the ability to get people to do what you want them to do regardless of social and legal limits that may exist. It is about getting people to act or behave in line with your own interests or desires rather than following their own autonomous decisions. This definition of power allows us to differentiate it from authority.

Authority is then the influence over the behaviours of others but *within* prescribed limits set by the specific authorities of a practitioner's role. In turn, the authorities of a role are defined by the policies and procedures of the service as well as the legal and ethical frameworks set out by governmental and professional bodies.

It can be deduced from these definitions that the use of power by mental health practitioners is not desirable as it leads to an autocratic and patronising style of working. Individual practitioners will make up their own minds about what is in the best interests of their clients. This style of working is open to abuses where coercion of vulnerable people and suppression of their viewpoint becomes more likely. It also inevitably leads to greater conflicts between practitioners and service users as they resist coercion or manipulation by practitioners.

The exercise of authority, on the other hand, leads to greater accountability of practitioners, as it is clearer what is acceptable and unacceptable in practice. Practitioners have to bring more negotiation to their style of working and be much more mindful of people's rights. Having greater clarity about what is authorised and unauthorised behaviour enables a more open debate about the validity of the practitioner's authority and allows service users legitimate means to challenge that authority if they feel that they are being treated unfairly.

Equality and diversity

The equality equation

The appropriate use of authority by practitioners is essential for good practice in mental health due to potential actions of restricting a person's right to self-determination or denying their liberty at times of severe mental distress. If practitioners exercise appropriate authority with respect for diversity, people who are vulnerable to oppression would be positively valued. Practitioners are then more likely to engage in behaviours that promote equality and challenge discrimination. The process can be summarised in the following way:

Authority + Diversity => (+) Values

Diversity

Valuing diversity involves understanding cultural differences. Culture is a complex concept and cannot be captured by a few facts and bits of knowledge. A little learning can certainly be a dangerous thing. The temptation in learning about other cultures is to oversimplify and leave people with the false impression that they now 'know' about a particular culture. Such simplistic thinking leads to assumptions about individuals from a culture and further compounds the problem of cultural stereotyping. The process is particularly dangerous in mental health work where far-

reaching decisions are made on the basis of interpretation of a person's behaviour as being atypical or 'anti-social'.

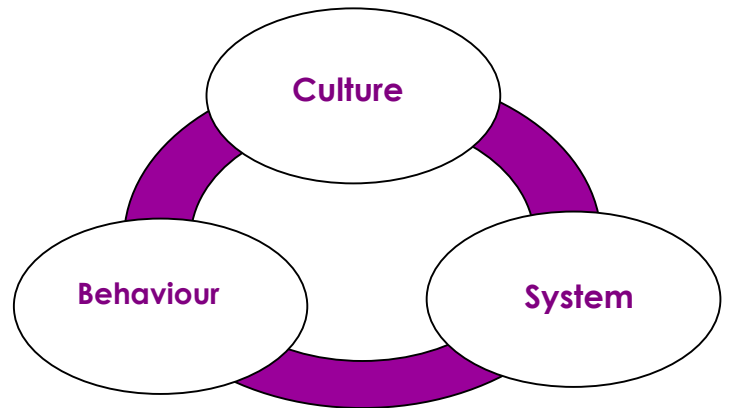
Cultural difference must be set within the current political context of our society if valuing diversity is to be meaningful. Witness the change in perception of the cultural difference of being a Muslim post-11 September 2001. Valuing diversity becomes just another vacuous phrase in policy documents if it is not linked to a wider strategy for promoting equality that takes into account issues of power and structural inequality in communities. Diversity and equality have to be linked in a strategic approach to service development.

Organisational change

Service development will not take place unless there is a coherent approach to organisational change. A lot of policies and strategies about equality and valuing diversity have resulted in little or no concrete changes in services. Hence we have not seen any real improvements in mental health services for Black people over the past 25 years. Research studies continue to present a static picture of Black people's experiences in mental health services. The problem of poor progress in improving services for Black people is part of a larger problem of managing change in public sector organisations.

Any social model of mental health must propose a coherent approach to organisational change and service development. Many models of services deal only with the behaviours of practitioners. Coherent change means that organisational culture – systems as well as behaviours of practitioners – must be addressed. Cultural values, beliefs and assumptions underpin the design and operation of systems in an organisation. Systems drive behaviours of the employees

operating them and in turn, behaviours are inter-linked with the culture of the organisation. All three components of organisational change have to be managed effectively to challenge institutional discrimination and achieve real improvements in services.



Professionalism

It is not only organisations that have to change to tackle racism, the whole concept of professionalism has to be re-evaluated and redefined. Professionalism from a Black perspective primarily has to be about increasing service user autonomy. It is an outcome-oriented approach and not just about inputs such as technical expertise and knowledge, although these aspects of professionalism are still important. What is being posited is an expansion of the concept of professionalism to respond to a more holistic formulation of what professional practice should entail.

Achieving greater service user autonomy involves a different mode of operation for mental health professionals. It means being in alliance with service users to defend a truly independent stance against forces that threaten the rights and interests of devalued and vulnerable groups. It is a stance that will not always be politically popular or in agreement with the government of the day but

professionals must be prepared to go the extra 'hard yards' if they are really committed to the purpose of their work. If mental health professionals are not prepared to share the struggle and pain of their service users they should seriously question whether they are doing the right work.

At the heart of the transformation of professionalism there must be a commitment to critical self-reflection. Professionals must be prepared to question their basic assumptions and identify their own prejudices and stereotypes about people. They must be prepared to analyse their decision-making and make more explicit the criteria and values underpinning decisions. They must also be prepared to be challenged by service users and others and regard this process as part of a learning process for themselves.

The focus of professional work must shift fundamentally from a crisis-oriented approach to a preventative one. There has been a great deal of debate about the importance of a preventative approach but professional structures, systems and procedures and even training continue to be focused on crisis work. Techniques and models of preventative work still seem to have a lower status in relation to crisis work, evidenced by the tendency to leave preventative work to under-funded self-help, voluntary and independent organisations.

The capability of professionals must be judged in the context of diverse communities, and competences for mental health work must be formulated with anti-oppressive practice as an integral part of good practice. There needs to be a clearer definition of professional authorities and what constitutes the appropriate use of authority. Capability must also mean the proactive promotion of equality and the valuing

of diversity and not just reactive anti-discriminatory practice.

Participation

Participation of service users in mental health services is a prerequisite for any social model approach but it is particularly important for a Black perspective as a safeguard against culturally inappropriate services. It should be recognised that any process of participation needs to allow for varying degrees of participation. Black service users initially may be quite reticent or cynical about participation given past experiences of services. The credibility gap may take some time to bridge.

The first step is usually to build *capacity* for participation among Black service users. In the mental health field, there is no established track record of involving Black service users in any systematic or meaningful way in service development and delivery. This is also sadly true in the service user movement itself. Given this background, it is going to prove difficult to achieve genuine participation of Black service users in mental health services. However, this is precisely what is required across a range of areas in service provision. To make real progress in dealing with institutional racism in mental health services, Black service users need to participate in:

- audit and quality assurance work
- service design and development
- training of practitioners
- research into services.

Five challenges for mental health services

I have identified some prerequisites for a social model approach that incorporate a Black perspective. The prerequisites form the elements of *how* change can be achieved, but what *outcomes* are required from future mental health services from a Black perspective?

Many years of talking to and working with Black service users and their families has highlighted specific themes in what is wanted by them from mental health services. These themes can be usefully expressed as challenges for services as Black people struggle to get assistance at times of distress. If mental health services are not to further compound the experiences of oppression, marginalisation and alienation that many Black people in mental distress face in society, they must meet these challenges. The challenges represent an agenda for action to improve mental health services based on a social model approach for Black and ethnic minority people. The five challenges are:

- humanity
- equality
- creativity
- accessibility
- practicality.

Humanity

The quality of human relationships between service users and practitioners is an essential factor in any type of mental health intervention. No amount of technical expertise or even financial resources can compensate for a lack of trust, credibility or respect. Black service users have constantly asked for practitioners to be more in touch with their own humanity and vulnerability to distress. One Black service user put it to me that practitioners frequently refer to the lack of 'insight' of service users but rarely seem to have 'insight' into their own behaviour.

Practitioner teams should enable their own members to talk about their feelings in doing mental health work. Although very rewarding work, it is demanding, and that has to be acknowledged. Colleagues need support emotionally as well as professionally. Service organisations should publicly reflect the importance of human relationships in the work through explicit 'values statements' and policies. For example, *continuity* of relationships in mental health services is of

great concern to Black service users and has a direct impact on the quality of relationships. Practitioners will also find the work more rewarding if they are able to form longer-lasting relationships with service users as real people rather than experiencing a string of human 'snapshots' of some 'diagnosis' or other.

There are many more things that connect us to someone from a different culture than separate us. White practitioners must not let the fear of racism de-skill them and must maintain faith in their own capability. It may sound basic, but a sense of humanity is vital for mental health work. It is what connects practitioners with people using services and is a fundamental building block for a constructive and helpful relationship.

Equality

One of the biggest challenges for the future is to develop truly inclusive mental health services that are appropriate for everyone not only in terms of race and culture but also in relation to gender, sexuality, disability and age. A holistic approach to equality will avoid any hierarchies of oppression while acknowledging the differences in causation and needs between the various groups in society who are vulnerable to oppression. There are some fundamental processes that are common to all forms of oppression, and practitioners need to guard against discrimination on personal and institutional levels. Practitioners also have to work with people based on an understanding and respect for their cultural context.

Teams should value the diversity of their members and enable colleagues to challenge each other constructively around equality issues. Service organisations have to create policies and systems to ensure a strategic approach to equality and work with communities to remove discriminatory barriers

to Black people being valued members of their communities.

Creativity

Black service users need to have a greater range of service options available to them; therefore more creativity is required in service development and delivery. Practitioners must work with Black service users to come up with creative solutions to problems. This will lead to services being more responsive to Black service users and enable practitioners to individualise packages of assistance. Teams can support creative approaches to working by allowing practitioners to take risks where necessary and establish a safe work environment where people can learn from any mistakes.

Service organisations can support creativity by ensuring that practitioners have sufficient authority to make important decisions about their interventions and bring decisions about funding closer to the individual service user. Mental health services also need to work more closely with Black and ethnic minority communities to involve a wider range of people in helping to tackle mental distress in those communities.

Accessibility

Black and ethnic minority service users have had a long-standing problem of not getting adequate information about existing services in the locality and not having sufficient choice of culturally appropriate services when access is gained. Practitioners have to inform Black service users and families about what services are available using different formats and languages. Teams can help colleagues to develop more culturally appropriate services through project work and aggregate information about the unmet needs of Black people in mental distress.

Organisations should review their systems for speed of response and eliminate any 'red-tape' that may slow down or restrict access for Black communities. Mental health services could be more proactive in training and educating other local community service providers to open up more ordinary community resources to Black people in mental distress.

Practicality

All service users, including Black service users, give a high priority to a variety of practical forms of assistance to do with finances, employment, general health, accommodation, training and education. Practitioners must ensure that they advocate for Black service users in getting practical help, particularly as Black people have traditionally had poor access to a range of welfare and preventative services including information about welfare benefits. Teams should ensure that practitioners are well informed about local services that provide practical help. Organisations have to develop assessment and person-centred planning systems that are holistic in their approach and give the practical needs of people a high priority.

Conclusion

The failure to eradicate institutional racism from mental health services in the UK over the past 25 years has been little short of spectacular. Despite a great deal of rhetoric and some pockets of excellent practice, the overall picture remains stubbornly the same. It can be argued that we have even taken a step backwards with the reform of the Mental Health Act, which holds greater potential for discrimination against Black people, especially Black men who are most vulnerable to compulsory treatment under the Act.

We need to understand the historical roots of the current problems for Black people in mental

health services or we will be condemned to repeating past mistakes. We must not waste the opportunity to formulate social models of mental health that incorporate a Black perspective, value diversity and promote equality for all. There have been numerous studies, local and national, that have laid out what Black service users want. Services must now meet the challenges that have emerged with actions not just words. There have been too many broken promises. If you lead people down too many false trails there comes a time when they will stop going along with you.

'Scientific bureaucracy' appears to be on the march once again in health and social services; we must not let the drive for 'evidence-based' approaches detract from putting service users at the centre of services. We need to listen even more closely to Black service users at this time of flux and transition in the development of mental health services. If we can get it right for groups of people that have been traditionally poorly served then we can get it right for the vast majority of people. Let's stop and take direction from service users for once.

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What is recovery? *Slides from a presentation by Jan Wallcraft, Sainsbury Centre*

What is Recovery?

- The ability to live well in the presence or absence of one's 'mental illness' (or whatever people choose to name their experience)
- Recovery happens when people with mental health problems take an active role in improving their lives, communities include them, and services enable the interaction.

What's new about recovery?

- Holistic concept -moves away from medical thinking of 'treatment' and 'cure'
- Based on personal empowerment and vision
- Resolves tension between 'negativity' and 'realism' - encourages hope despite ongoing disability or impairment
- Encourages services to work together in support of the person's own life journey.

Recovery definition

'Recovery' is a process, not a place. It is about recovering what was lost; rights, roles, responsibilities, decisions, potential and support. It is not about symptom elimination, but about what an individual wants, how to get there and how others can help. Its is about rekindling hope for a productive present and a rewarding future - and believing one deserves it. Recovery involves having a personal vision of the life you want to live, seeing and changing patterns, discovering symptoms can be managed and doing it, doing more of what works and less of what doesn't. Recovery is about reclaiming the roles of a 'healthy' person rather than a 'sick' person. Recovery is about getting there.

Problems with Recovery model

- Recovery from what?
- Recovery to what?
- Whose recovery is it?
- Dangers of professional adoption of the terminology without real shift in power dynamics between service user and system.
- How can we build and maintain a concept of recovery owned by users?

Recovery principles

- Hope/encouragement and support
- Coming to terms with the past
- Taking personal responsibility for life
- Acting to rebuild one's own life
- Developing valued relationships/changing other's expectations
- Perseverance/finding meaning & purpose.

What needs to change

No one can make another person recover. Caring others, well-intended helpers, and service providers can help to spark, nurture and fuel the embers of recovery that burn in each person. Service providers must be cautious about 'recovery programs'. Recovery-supporting policies and practices cannot simply be tacked onto existing services. Supporting the recovery of others means fundamentally doing differently that which we do everyday. (Curtis 1997)

Language and Recovery

Historically, language has been the principal tool that has served to separate people with labels of differentness by defining the needs of these people with a label as fundamentally different from those of other citizens. In this way, language keeps oppression intact. Therefore an important way to change these negative stigmatizing beliefs and behaviours is to change the language. (Carling 1994, Return to Community)

Developing the Recovery vision

- Recovery in wider context - need to tackle practical issues of benefits/diagnosis/existing limits to user choice and power.
- Fund voluntary and user-led recovery projects to unleash creativity and vision
- Recovery vision offers opportunities to break up old medical dominated hierarchies to form new alliances and partnerships with users/families/voluntary sector.

Telling our own stories

'The press tends to portray people with mental health needs as victims or aggressors. I believe that in the future, more and more users will be given the chance to tell their own individual stories, as I have, and this will hopefully lead to greater understanding and acceptance by society'

From 'Something Inside So Strong' Jim Read (ed), MHF 2001

Personal perspectives

- **Susie.** I don't see myself as sick. I mean I hear voices and experience physical rushes and I have vivid dreams and fantasies. I hear nice voices, hilarious. Often very humorous, yeah. I have flashes and I paint them. They're brilliant...It's a privilege, it's not a disability,
- **Patte** I experienced it as a mystical experience...something extraordinarily wonderful...knowing that life had purpose and meaning, and that *my* life had purpose and meaning. It changed my life.
- **Vince.** I'd rather listen to somebody who treats it as an educational challenge rather than an illness. That's a distinction that I found very useful, because I never had to consider myself ill...I only had to consider myself as having a lot to learn. That meant my experiences were, in a way, validated.



Women: a social inequalities perspective

Jennie Williams, Tizard Centre, University of Kent

Aims of this presentation

- To provide a reminder of what women want from mental health services
- To look at how services can develop to meet these needs

Evidence from direct experience: UK survey findings¹

Number (percentage) of respondents (n=96)

Services don't meet women's mental health needs	39 (40.62%)
Services replicate inequalities	30 (31.25%)
Services are unsafe for women	29 (30.21%)
Dominance of medical model	18 (18.75%)

Services don't meet women's mental health needs

"Our needs are ignored, we are treated as illnesses."

"What is needed is a complete overhaul of existing service provision from a starting point of what women need – at present women get squeezed into what exists which doesn't fit women and mis-treats women's mental health symptoms."

Services replicate inequalities

"Women's mental health issues appear to have a lower status and services rely heavily on professionals having a personal interest."

"Often the needs of women (& minority groups) are ignored and subsumed within the needs of men and majority groups."

Services are unsafe for women

"I often meet women who have been re-traumatised within mental health services, e.g. through being physically or sexually assaulted or through the threat of violence."

"I feel threatened by men, they get more angry and I've been sexually assaulted by a man whilst on the ward. When I need to use the bathroom at night there are often men wandering in the corridor."

Dominance of medical model

"Not taking account of the specific stresses & difficulties which women face. Not taking time to understand a woman's history & experience & the complexities of these. Only offering medication. Not offering talking treatment/culturally appropriate treatment. Pathologising women who do not follow gender norms in lifestyle/behaviour."

"I would also like to see approaches used in response to the distress (and resulting chaos) that promote independence and empowerment as opposed to those that seek to remove responsibility and control from women."

In summary

There is evidence that mental health services:

- don't meet women's mental health needs
- often replicate inequalities
- can be unsafe for women
- are overly dominated by the medical model
- are very insensitive to the effects of gender and other social inequalities.

What is social inequality?

- Social inequality exists when an attribute such as gender, race or class affects access to socially valued resources including money, status and power.
- Dimensions of social inequality define power relationships that serve one group at

¹ Williams *et al.*, 2001

the expense of another – there is fundamental conflict of interests at their core.

- Social inequalities structure society and are deeply embedded in our personal identities – they can be difficult to speak about and hard to change.

How we know about social inequalities and mental health

- Long history
- Largely produced since the mid 1960s
- Driven by social movements
- Mainstream social institutions have played only a minor role in knowledge development
- An extensive literature has been generated

Characteristics of this knowledge base

This literature is mainly to be found at the margins:

- uneven and fragmented, and often uni-dimensional
- contains different types and sources of knowledge
- often regarded as abstract and polemical, and is easily trivialised, marginalised and ignored
- often assumed to be irrelevant to the needs of people using and providing mental health services

Social inequality and mental health

Overview of the relationship:

- inequitable access to resources
- processes of subordination
- serious abuses of power

Key findings

Inequitable access to resources

Inequalities in our society means that substantial numbers of women because of their gender, race and class, and age, have

restricted access to resources known to affect mental health, these include:

- money
- work
- leisure.

Resources – money

- The mental health implications of income are well substantiated²
- Poverty and social deprivation are affected by social inequalities based on gender, race, age and disability, e.g.
 - women working full-time earn on average 82% of the hourly earning of men
 - women's gross income is on average 49% of men's³
 - over two million employees have weekly earning below the lower earning limit⁴ — four-fifths of these are women⁵
 - women pensioners receive the lowest gross average weekly income in Britain⁶
 - a recent study found that nearly half of young lone mothers who are poor report less than good health.⁷

See below for highest and lowest paid occupations in Great Britain.⁸

Resources: paid work

- The overwhelming majority of women work in the service sector in jobs that mirror domestic work.
- Women who combine paid employment with caring for children or other dependents are restricted to part-time, low-paid employment.⁹

² Acheson, 1998; Wilkinson, 1996; EOC, 2002;

³ ONS, 2002 p. 91

⁴ £64 per week in 1998-99

⁵ EOC, 1998 p1

⁶ EOC, 2001a

⁷ EOC, 2001a

⁸ ONS, 2002, p.93

⁹ EOC, 2001b, p.1

Highest and lowest paid occupations in Great Britain April 2000

Average gross weekly pay (£)

Highest paid

Treasurers and company financial managers	1,059
Medical practitioners	964
Organisation and methods and work study managers	813
Management consultants, business analysts	812
Underwriters, claims assessors, brokers, analysts	775
Police officers (inspector or above)	766
Computer systems and data processing managers	757
Solicitors	748
Marketing and sales managers	719
Advertising and public relations managers	690

Lowest paid

Educational assistants	212
Other childcare and related occupations	205
Counterhands, catering assistants	196
Launderers, dry cleaners, pressers	196
Hairdressers, barbers	190
Waiters, waitresses	189
Petrol pump, forecourt attendants	189
Retail cash desk and check-out operators	185
Bar staff	184
Kitchen porters, hands	184

- 67% of working mothers with children under 5 are in part-time jobs, compared with 3% of fathers.¹⁰
- 25% of British families are headed by a lone parent – 90% of these are women.¹¹
- In the past 25 years there has been an increase in the poverty of mothers, and lone mothers in particular.¹²
- Women from all ethnic minority groups are less likely to be in paid employment than are white women.¹³
- The economic activity rates for women and men with disabilities is 48% and 53%, compared with 78% and 91% for women and men who are not disabled.¹⁴

¹⁰ EOC, 2002, p.14

¹¹ EOC, 2001a, p.3

¹² EOC, 2001a p.3.

¹³ CRE, 1997

¹⁴ EOC, 2000a p.4

Resources: unpaid work and leisure

- Research shows that married men report doing about 9 hours of 'housework' per week while their wives report an average of 24 hours.¹⁵
- This division of labor has remained identical between 1986 and 1996.¹⁶
- Men do less than half the childcare women do (even where all feeding, washing clothes and cleaning up is counted as housework not childcare).
- Caring for children and dependent relatives carried high costs when associated with isolation, low social value and a lack of resources.¹⁷
- Marriage is more likely to be beneficial to the psychological well-being of men, and detrimental to the psychological well-being of women.¹⁸

Processes of subordination

- Processes that characterise inequality between social groups are known to have mental health consequences,¹⁹ e.g. exploitation, discrimination and oppression.
- Processes that help perpetuate inequality between social groups have mental health consequences, especially those that hide injustice and its effects on lives and experiences, e.g. victim blaming,²⁰ and labelling attempts to deal with oppression as 'madness'.

Experiencing oppression

Such internalised racism means we may start to dislike and despise who we really are, at the

¹⁵ Seymour, 1992; Pilcher, 2000

¹⁶ Seymour, 1992; Pilcher, 2000

¹⁷ Macran et al, 1996; Smith 1991, Platt et al, 1990

¹⁸ McRae and Brody, 1989;

¹⁹ Busfield, 1996

²⁰ Penfold and Walker, 1984: Burstow, 1992.

same time feeling guilty for being so despicable and part of such an unacceptable cultural group. So we may try to deny who are and distance ourselves from our family and community. But our black skin will always remind us (and others) of the truth of our being and we will know in our hearts that we will first and foremost always be seen as black and may never be accepted on truly equitable terms. This may result in feelings of confusion, vulnerability, powerlessness and hopelessness, with subsequent emotional and psychological distress often accompanied by self-destructive feelings and (in some cases) psychotic disturbance.

(Trivedi, 2002, p.76)

Serious abuses of power

- In the context of gender relations the mental health implications of physical and sexual violence and abuse, perpetrated overwhelmingly by men, are now very well substantiated²¹
- Research shows that between 1 in 10 and 1 in 3 girls experience sexual abuse in childhood (depending on the definition of abuse and what age childhood is deemed to end): this can have profound mental health consequences
- Twice as many girls as boys are abused sexually.
- The abuse of girls is more likely to be perpetrated by family members, to begin in early childhood and to occur repeatedly.
- In Britain 1 in 4 women experience physical violence perpetrated by a partner at some time in their lives
- 1 in 7 women suffer rape in marriage
- The evidence from large-scale prevalence studies is that levels of sexual and

²¹Davidson et al, 1996; Goodman et al., 1998; Harris and Landis, 1997; ²Goodman et al.1995a; ³Adshead, 1994

domestic abuse do not vary significantly between economic or ethnic groups.

- Physical and sexual assault are normative experiences in the lives of women who have serious mental health problems who are homeless or living in high security psychiatric services.

Equity and mental health service provision

Women are:

- less likely to be offered the more highly valued treatments in community and hospital based service provision²²
- more likely to receive forcible treatment with drugs²³ and ECT²⁴
- more likely to be abused and neglected within services²⁵
- less likely to have their physical health needs taken seriously²⁶
- more likely to be untrusting in their attitudes towards services²⁷
- more likely to experience services as re-victimising.

Taking Action

Learning from good practice

- The feminist literature has always been closely associated with the development of interventions aimed at supporting women to find ways of surviving that are less personally damaging.
- Included within the range of concern of feminist practitioners are:
 - sexual and physical abuse²⁸
 - self-harm²⁹
 - eating disorders³⁰

²²Commander et al, 2000; Williams, 1999

²³Commander et al, 1999

²⁴DoH, 1999;

²⁵Warner and Ford 1998; Williams and Keating, 2000

²⁶Williams, 1999

²⁷Keating et al, 2002

²⁸Burstow, 1992; Harris, 1998a;1998b

²⁹Babiker and Arnold, 1997.

³⁰Mirkin, 1990.

- depression³¹
- And to a lesser extent:
 - severe psychiatric difficulties³²
 - and ‘personality disorders’³³
- Service developments³⁴ within the Black community indicate that Black people value services that embrace:
 - identity
 - cultural traditions
 - lived experience
- Service development that have been fuelled by the mental health user movement³⁵ typically value:
 - shared experience and understanding
 - equality
 - mutual aid and self-help

Mainstreaming social inequality

- It is an understanding of the mental health implications of social inequalities that needs to be mainstreamed within mental health services through, e.g.
 - training
 - changes in the workplace culture
 - thoughtful implementation of the new DH strategies
- This is crucial for developing a capable workforce and for empowering mental health staff
- There are risks of singling out sub-groups of the clinical populations
- It is social inequalities that pose the major problem to mental health for men as well as women

- But identifying social inequalities as a cause of mental health problems:
 - is incompatible with the medical model & individualistic psychological models
 - challenges the power base of the mental health professions
 - can be experienced as disempowering by mental health staff.

Summary

I have:

- Noted the concerns women have consistently expressed about mental health services
- Linked these concerns to the reluctance of mental health services to accept that gender and other social inequalities are a mental health matter
- Added to women’s voices by summarising some relevant research
- Argued that while I support the demand from the DH to take “Women’s Mental Health Into the Mainstream”– it is crucial that we do this from a social inequalities perspective.

See next page for references.

³¹ Holland, 1995

³² Mowbray et al, 1998.

³³ Becker, 1997

³⁴ Keating, 2002; Keating, In press

³⁵ Lindow, 1999

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Lesbian and gay perspectives on mental distress

Sarah Carr

Thus psychiatry has its own blind spot. It may see only one dimension of the doctor-patient dialectic: the disease or demon within the sufferer. What patients' narratives particularly highlight are the demons without, amongst which the madhouse-keeping psychiatrist himself, his techniques and his milieux, may well all too readily figure as the final instance.

Roy Porter *A Social History of Madness*, p.25 (1999)

Firstly I'd like to say that when I talk to you today it's not as an employee of the Social Care Institute for Excellence (SCIE), but as myself. I'm a recent member of the Social Perspectives Network and noticed that although the draft programme mentioned lesbian and gay perspectives, no one had been found to give that perspective. As a gay person who experiences mental health problems I felt I could contribute something to the discussion, so I made my offer and it was accepted. It's not often that gay people are represented in a forum like this so I felt I wanted to 'do my best'. It took me a while to work out how to approach this topic. The academic in me wanted to give you a lecture on the history and theory of homosexuality in the psychiatric movement. But I thought that almost anyone could come and talk about the social construction of madness, moral control and the myth of mental illness, if they read the right books. Eventually I came to the conclusion that the value of having me here today is that I can tell what it's been like. So I'd like to share some of my experiences and thinking with you. I'll begin with my personal experience and try to place it in a wider context in order to gain some understanding of why social perspectives are important to gay people with (or without) mental health problems.

When I was 18 I was very unwell. I was self-harming, neglecting to eat properly, wandering and experiencing the feeling that I was becoming transparent or physically

disappearing. Social relationships and sometimes even speaking were difficult for me. During my first term at university the execution of my plan to kill myself was, now thankfully, interrupted. Eventually, a friend persuaded me to seek the help of a psychotherapist. This was my first encounter with therapy proper and I had no idea of what to expect. I was also very vulnerable. By the end of the first consultation the therapist had discovered my sexual orientation, which provided him with the disease to cure. Because I wasn't all that happy about my sexuality at that stage, I complied with him. Thus our therapeutic project became my 'heterosexualisation', the idea being that if I became heterosexual then I would be cured of my mental distress. My homosexuality was my illness.

My therapist's method for diagnosing my 'latent heterosexuality' was novel to say the least. He showed me several examples of top-of-the-shelf pornography designed for heterosexual men and concluded that because I didn't find these images sexually appealing, I couldn't really be gay. Thinking about it now, this strategy is a curious variation on the traditional methods of aversion therapy. Up to the late 1970s gay people, men in particular (who were sometimes referred by the criminal courts for treatment), were given aversion therapy which consisted of electric shocks or nausea-inducing drugs coinciding with the presentation of homoerotic images. My therapist showed me pornographic images of women to which I had

an inherent aversion. He then tried to use hypnosis to reinforce and generalise this feeling and to coax my repressed heterosexuality into returning. However, my resistance to his attempts to hypnotise and avert me into a more 'healthy' state of *at least* bisexuality forced him to conclude that I had some sort of personality disorder.

I may have been spared the electric shocks and nausea, but the fundamental idea was still the same: homosexuality is a disease of the mind and is the biomedical cause of mental illness, if not the illness itself. To me the medical model of homosexuality to which I was subjected during my treatment was actually harmful and eventually I found it less damaging to continue coping with my distress by self-harming. It was 1990 and at that point in time my therapist was not just following his own idiosyncratic approach. His method could be endorsed by reference to the World Health Organisation's International Classification of Disease, which, until 1992 – that's only 10 years ago – classified homosexuality as a disease under section 302, 'sexual deviations and disorders'. It was finally removed from the British central database of mental illnesses in 1994.

Even when homosexuality had been officially removed from international disease classification, I still found it difficult to find the support I needed. In fact, my experiences taught me to avoid mental health services when I became unwell. At times I have felt too vulnerable to risk seeing a doctor. The fact is that many mental health practitioners still operate using the disease model of homosexuality because it is integral to their inherited clinical thought and practice. This can then be compounded by the personal religious

beliefs or moral prejudices of the individual. For example, my therapist was a Roman Catholic man and so, I believe, had an additional religious motivation for curing me. Obscurely, he felt me to be a wasted womb. My depression came from my inability to recognise that I was not complete without a male sexual partner. My experiences have led me to believe that the claim of therapists and doctors to professional objectivity can often be a false one. I have met with clinicians whose religious, moral and social prejudices have prevented them from recognising me as a human being trying to manage difficult and complex experiences. They have been unable to resist trying to cure me through the manipulation of my sexuality. Sadly, my experiences seem to exemplify a general situation.

Research published in the British Journal of Psychiatry in 2001 indicated that lesbian and gay patients "may encounter overt or covert bias, including the pathologisation of homosexuality *per se*," when receiving psychotherapeutic treatment on the NHS.³⁶ In 1997 a MIND survey reported that 78% of lesbian and gay respondents "expressed reservations about feeling safe enough to disclose their sexuality within a mainstream mental health service," and 84% said that they "feared prejudice, discrimination or that their sexuality would be pathologised." 88% of respondents who experienced prejudice and discrimination within mental health services felt too vulnerable to challenge it.³⁷ The groundbreaking 1998 study by Linda McFarlane on the experiences of lesbians, gay

³⁶ Butler A, King M & Phillips P (2001) Straight talking: an investigation of the attitudes and practice of psychoanalysts and psychotherapists in relation to gays and lesbians *British Journal of Psychiatry* 179 pp.545-549

³⁷ Golding J (1997) *WithOut Prejudice: MIND Lesbian, Gay and Bisexual Mental Health Awareness Research* London: MIND Publications

men and bisexuals in UK mental health services concluded that “lesbian, gay and bisexual mental health service users are discriminated against and oppressed, not only by the attitudes and behaviour of society at large, but also from within mental health services.” The report found that, like me, gay people sometimes choose to avoid mainstream mental health services because they are afraid of being “pathologised, negatively judged or stigmatised.”³⁸

McFarlane’s study showed that there is a connection between sexual orientation and mental health problems. However, it is radically different from the biomedical disease model. The report showed that homophobia (that is, fear-induced prejudicial behaviour towards or discrimination against gay people) and heterosexism (the assumption that everyone is or wants to be heterosexual) have an impact on mental health. She writes that, “difficulties in coming out compounded feelings of loneliness and isolation, guilt and fear and led in some instances to feelings of depression, self-harm and attempted suicide.” This is where understanding through social perspectives becomes vital. The truth is that gay people can experience mental distress because of their sexual orientation, but this has nothing whatsoever to do with diseases of the mind. In 1994 MIND’s Equalities Group issued this statement: “The myth that sexual identity alone is either a cause or symptom of mental distress must be revealed and repudiated. We recognise the cumulative effect of discrimination in all our social systems...”³⁹ Through the modern social model, the medical model can be seen as one of the many social factors that can impact on a gay person’s mental well being and sense of self.

³⁸ McFarlane L (1998) *Diagnosis: Homophobic. The experiences of lesbians, gay men and bisexuals in mental health services* London: PACE

³⁹ MIND (2001) *Lesbians, Gay Men, Bisexuals and Mental Health Factsheet* London: MIND Publications

Before I had a lesbian therapist, I had never been encouraged to explore how social and cultural experiences of being gay may have shaped my sense of self, and influenced my mental health. I had never felt safe enough to do so in any mental health service context. It was even tempting to avoid the topic altogether or deny I had any negative feelings about being gay. As one therapist observed about a gay client:

“I saw the client for six years. Initially he denied absolutely that his sexual preference was an issue...it seems an understandable defensiveness in the context of the pathologising of gay sex...only after two or three years were we able to look at what it meant to be gay... Ultimately we reflected long and often on how his personality had been influenced by both his culture’s hostility to homosexuality and the identity he often felt forced to adopt by his own cultural gay norms.”⁴⁰

It doesn’t take the combined intellects of Freud and Jung to conclude that as a self-aware gay teenager living in a Catholic household, attending a religious school, with regular exposure to her father’s *Daily Mail* while it was running the virulent anti-gay hate campaign which resulted in Section 28, I was at risk of developing a few problems with what is known as ‘internalised homophobia’. Recognising the social issues that connect with my own mental health problems has helped me to stop blaming myself entirely for the distress I feel. Unfortunately, statutory mental health services have not helped me in this process of recognition.

Of course, social factors can be positive as well as negative. The love, acceptance and support

⁴⁰ Butler A, King M & Phillips P (2001) *Straight talking: an investigation of the attitudes and practice of psycho-*

I have enjoyed with my partner and friends have been profoundly important in the formation of a positive identity. I have found that sharing negative experiences with other gay people and transforming them through humour to be very affirming. The normalising experience of being with people who accept me for who I am has been very significant. I have, like many other gay people, formed my own 'chosen family' because my biological family is too often the site of denial, conflict and distress. Finding a lesbian therapist has meant that I have been able to positively benefit from therapeutic treatment, because my sexuality is not a problem for or to her. Unfortunately, I had to wait for years until I was in the financial position to afford her.

Mental health services should encourage self-acceptance and the construction of a positive sexual identity rather than promoting self-loathing and the compulsion to change. Both academic research and user experience indicate that it is the experiences of rejection, isolation, discrimination and oppression that can make gay people vulnerable to mental distress. Instead of helping to alleviate it, mental health professionals can actively add to this distress. Very recently, the Department of Health issued a document detailing plans for the strategic development of mental health care for women, which included explicit reference to the vulnerability of lesbian and bisexual women. The analysis was based not on a medical model, but rather recognises the influence of social factors on mental health. The document states that "women who do not define themselves as heterosexual may have added stressors in their lives given the degree of stigma prevalent in society."⁴¹ This is a

promising start, but in mental health practice the disease model of homosexuality still needs to be challenged on a fundamental level. Mental health professionals need to be educated about the social influences on the mental health of gay people and to recognise that their practice can be compromised by personal prejudice. Through the work of researchers, campaigners and specialist mental health agencies like the Project for Advocacy, Counselling and Education (PACE), the mental health needs of gay people are very slowly beginning to be recognised. How these needs will be addressed within statutory mental health services remains to be seen.

Essential reading

- Golding J (1997) *WithOut Prejudice: MIND Lesbian, Gay and Bisexual Mental Health Awareness Research* London: MIND Publications
- McFarlane L (1998) *Diagnosis: Homophobic. The experiences of lesbians, gay men and bisexuals in mental health services* London: PACE (ISBN 0952941119)
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http://www.mind.org.uk/information/factsheets/L/Lesbian/Lesbians_Gay_Men_Bisexuals_and_Mental_Health.asp
- Price J (1997) *Queer in the Head: An examination of the response of social work mental health services to the needs and experiences of lesbians and gay men* Surbiton: University of Warwick and SCA (Education) (ISBN 0901244708)

Project for Advocacy, Counselling and Education (PACE)

34 Hartham Road, London N7 9JL
Tel: 020 7700 1323 Fax: 020 7609 4909 e-mail: pac@dircon.co.uk

PACE offers counselling, groups, mental health advocacy, weekend workshops and employment initiatives for lesbians and gay men in greater London. They undertake HIV prevention work with gay men and training on HIV issues and on lesbian and gay mental health for voluntary and statutory agencies nationwide.



analysts and psychotherapists in relation to gays and lesbians *British Journal of Psychiatry* 179 p. 547

⁴¹ Department of Health (2002) *Women's Mental Health: Into the Mainstream. Strategic Development of Mental Health Care for Women*. London: Department of Health

About SPN

The Social Perspectives Network for Modern Mental Health (SPN) uses knowledge-based practice to:

- articulate and promote the value of modern social models in mental health services
- provide a focus for the sharing of best practice in social interventions in modern mental health services
- engage with and influence key policy makers to support the integration of social models in modern mental health services.

At the time of going to press in Spring 2003, SPN's hosting arrangements are due to be transferred from Topss England to the Social Care Institute for Excellence.

Social Perspectives Network

info@spn.org.uk

www.spn.org.uk