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IDENTITY CRISIS: MENTAL HEALTH USER GROUPS AND THE `PROBLEM' OF IDENTITY

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INTRODUCTION

One of the most fundamental objectives of user groups is to claim the right to self definition for those people whose identity and `problems' have been defined by professionals. Reclaiming the right to define themselves and their problems is a prerequisite for attaining other objectives. Participation within such movements can demonstrate that those formerly viewed as passive and dependant recipients of welfare can be actors capable not only of controlling their own lives, but also of contributing to shaping the nature of welfare services and of achieving broader social objectives. Participation can itself contribute to a surer sense of identity.

Nevertheless, making one's identity as a user of services visible may not be easy because of the stigma attached to such a status. In the case of people whose shared identity centres around their use of mental health services there are particular problems associated not only with the status of service user, but with the fear of madness. Whilst disabled people and disabled people's movements emphasise the importance of identifying as disabled people, debates around language amongst those involved in the mental health users' movement concern the nature of the relationship with services. The question is not whether the movements should be described as `mad people's movements' or `mentally ill or emotionally distressed people's movements', but whether they should describe themselves as `survivors' or `users and ex-users' of mental health services. As well as differences within the UK user movement on this issue, the European Users' Network has been debating this question as people active in user movements across Europe have come together to campaign at an international level.

Whatever decision groups make about the description which they feel most accurately reflects their experience, it is the use or survival of services, rather

than the experience of mental distress per se which usually provides the starting point for involvement in the movement. An exception to this is the `Hearing Voices' movement which is becoming an increasingly important forum within which people who hear voices can seek to make sense of this experience with others who share it.

This chapter will discuss issues relating to the personal and social identity of people who have experienced mental health problems and will consider how this affects the nature of groups which seek to empower people who identify themselves as users or survivors of mental health services. It will draw on research in which the authors are engaged which has studied groups of users, as well as published accounts of individual and collective responses to mental distress.

The research in which the authors are involved is part of a much wider ESRC funded research programme which is investigating the nature of changes in the governance of public services at a local level. The project is looking at the development of user movements amongst disabled people and people with mental health problems and how these groups are seeking to influence the purchasers and providers of health and social care services. It considers questions of civil rights, citizenship and consumerism (see Barnes, Harrison and Wistow, 1994, for a discussion of the project). Whilst the question of identity is not the prime focus for the research, the significance of individual and collective group identity has been a recurring theme within it. Similarities and differences between disabled peoples' groups and groups of people with mental health problems are considered elsewhere. In this paper we focus solely on mental health service users' groups.

PROBLEMS OF IDENTITY

We start by considering different factors which may affect the way in which someone who has experienced mental health problems feel about themselves and the way in which other people may respond to them. Unless otherwise indicated, the quotations are from interviews with people undertaken as part of the research referred to above.

1.   Personal and inter-personal factors

The nature of mental distress, which can manifest itself in many different ways, is such that it may itself undermine a person's sense of self and consequently their identity. People may experience extremes of sadness; of helplessness, hopelessness and of anxiety. At times they may feel elated

and have huge amounts of energy. At other times getting out of bed or getting out of the house may feel impossible:

> `My mood would change from day to day - you didn't know what to expect at all' (Ritchie et al., 1988, p. 5).

It may include experiences which are hard to make sense of and may make those who experience them afraid or confused, or which make it very difficult for them to get on with their lives:

> `I was so paranoid. I mean I used to duck and dive in hedges, you know. I used to think the IRA were after me, or if there was a murder on the television. I thought the murderer was following me, and every time the police caught somebody I used to feel relieved for a little while..' (Ritchie et al., 1988, p. 5).

Those sorts of experiences can make relationships with other people difficult. Unpredictable behaviour can cause others to be very cautious around people they know have mental health problems. The fear of others can lead to exclusion and rejection, which in turn can result in a wish to hide distress. Thus people may be unwilling to seek help for their distress or even to acknowledge it.

There is some evidence of a gender difference here. Men may find it particularly hard to admit to themselves or to others that a problem exists. This may be a partial explanation for the gender differences in statistics relating to alcoholism and acknowledged mental health problems (Barnes and Maple, 1992).

Stigma can lead to people attempting to hide the fact they have received treatment for mental illness:

> `... in other areas I hide it I have to confess. I have a lot of friends and people who don't know... it's the stigma of it.... If you ever told people that you'd been in, then the chances are they wouldn't want to have much to do with you. And I mean I have to admit before I was involved I felt along similar lines'.

Revealing a history of mental distress or breakdown can result in discrimination in the job market, in housing and in personal relationships. This in turn can result in difficult financial circumstances which further inhibit people's opportunities to become involved in activities which would enable social contact. Although as Prior (1995) has discussed, such outcomes may

not be inevitable if there are social and economic benefits for `ignoring' stigmatising labels.

The social nature of human beings means that identity is formed through interaction with others:

> `we build a self-conception of who we are through discovering what we are and are not capable of doing, an achievement based on participation in social life' (Doyal and Gough, 1991, pp. 50-51).

Feminist psychologists have emphasised the importance of recognising the significance of relating to others in terms of individual development. They have argued that, rather than seeing a need for building an identity around relationships with significant others as a sign of immaturity which is suggested by traditional, male models of psychological development, the ability to form such relationships should be seen as a sign of strength. (Kaplan and Surrey, 1986). Thus the social isolation experienced by many of those with mental distress can inhibit the development of self and identity and restrict opportunities for growth.

For some people being diagnosed as `mentally ill' is more acceptable than being labelled as `mad' because illness is less stigmatising than madness. However, others reject the notion of mental illness as being incompatible with their experience and they may find themselves being regarded as lacking insight as a result. If your own understandings of the nature of your experiences are denied by powerful others this can further undermine confidence in self:

> `But a lot of people who have mental health problems, they think they're not being believed and that's sad really. Because they know how they feel'.

Unlike physical impairment, mental distress may be a temporary or intermittent experience. The sense that this is an experience from which people hope that they might recover may mean that some people do not want to accept it as an identity which will determine a commitment to devote themselves to the user movement. However, many people who have experienced mental distress describe a fragility in their recovery. One said: `You never know when you stop being a user'. The effects of the experience stay with you for a long time; there is a fear that the mental distress will return and the experience of being admitted to hospital and all that that involves has a lasting effect on many people's lives. Unlike a spent criminal conviction, a

record as a psychiatric patient can affect people's prospects throughout their lives and consequently their social relationships:

> `Mind you it can always come back, even with a depression and breakdown... they fear they are labelled for life'.

These factors suggest that personal experience of mental distress may not only make it difficult for people to become activists within the movement, but also that the movement must respond to the personal as well as political aspects of the experience of mental distress and of receiving services. Some of the most powerful expressions of what it is like to be on the receiving end of psychiatric services which have inspired the development of user groups both in this country and elsewhere, have been very personal statements of the way in which individual experiences and the responses of others can challenge and undermine a belief in yourself and who you are. Judi Chamberlin (1988) and Kate Millet (1991) have published accounts of such experiences, but they are also to be heard whenever users speak on conference platforms and demand that the voices of those who have experienced emotional distress should be heard and respected.

2. *Structural factors*

There are a number of different structural factors which are significant in considering the status of people with mental health problems and which thus have consequences for their personal and social identity. Here we briefly consider the relevance of class; race; gender and age. We also discuss the power of mental health professionals in this context.

There is substantial research evidence of the relationship between mental health problems and social class, although whether being working class is more likely to lead to mental ill-health, or whether mental ill-health results in people `drifting' down to the working class is still debated (Warner, 1994). Warner argues that, whilst the political economy is clearly a significant factor affecting both the incidence of mental health problems and their outcomes, the relationship is not unidimensional. What is not in dispute is that mental health problems are clearly associated with socio-economic disadvantage which, together with the stress associated with material hardship, results in reduction of opportunities for social interaction and loss of self esteem with consequences for a person's identity:

> `... because once you've been say, branded as having been in one of those places realistically there is very little hope of getting a job no matter how well qualified you are..'

`I was now pushed into a situation while I was at (bed and breakfast hotel) where I was in absolute poverty. I didn't even have enough to live on. I had to go back to my parents with my hands out... after I'd supposedly broken away and become independent and learned how to manage for myself. It wasn't very dignifying' (Ritchie et al., 1988, p. 8).

Race is an important determinant of identity as well as affecting a person's social status and the likelihood that they will find themselves identified as mentally ill. There is evidence of difference in the use of mental health services by different ethnic groups, with black people of African or Caribbean origin most likely to find themselves subject to the controlling powers of mental health legislation (Barnes et al., 1990; Bowl and Barnes, 1990). Fernando (1991) has discussed the imperialism of Western psychiatry which has devalued explanations of experience and behaviour based in different notions of the person. He has considered how black people may find their cultural beliefs misunderstood and pathologised.

Few black people were involved in the three groups we studied in our research. Early in the project we made contact with the National Black Mental Health Association and heard of the difficulties the group was having in establishing a presence for black people within the mental health user movement. There are black user groups, but responses from people we spoke to during our project suggest that the user movement is currently primarily a white movement which may be unable to speak to the experiences of black mental health service users.

Gender is another structural variable which has substantial significance in relation to people's experience of the mental health system. Again, not only is it a question of unequal representation as users of mental health services, but the way in which mental distress is identified is affected by gender, as is the response of mental health professionals to those experiencing such distress (Barnes and Maple, 1992; Ussher, 1991). The `diagnosis' of mental disorder (in particular personality disorder) is affected by a perceived lack of conformity to stereotypes of female behaviour, whilst many constructs of mental distress are clearly gendered in nature: `hysteria' is an obvious example, whilst the category `housewives syndrome' has not long been erased from psychiatric textbooks and still lurks within the thinking of some practising psychiatrists. Sexual abuse has been acknowledged to be an experience which is a significant factor in the lives of many women who are admitted to psychiatric hospitals (e.g. Bryer et al., 1987) and provides a potent example of the way in which the oppression women experience in their everyday lives may translate into diagnoses of mental disorder and

result in treatment within the mental health system. Not being believed by clinicians when speaking of experiences of sexual abuse can further contribute to the abuse of women's sense of self within what is meant to be a healing environment. Women's identity as users of mental health services may thus be experienced in different ways from men's experiences and this needs to be acknowledged within the user movement.

Mental health problems can be experienced throughout the life span. There are ever-increasing numbers of older people within the population. 15% of people over the age of 65 are affected by depression severe enough to need treatment and 1 in 4 people aged over 85 experience dementia. For older people emotional distress may be associated with experiences of loss - loss of role; loss of physical health or loss of loved partners. These factors may make it more difficult to participate in valued activities and people may lose their motivation to do so. Losing a role as a worker; as a mother; as a lover can undermine older people's sense of themselves. For those who experience dementia the fragmentation of the self may be almost complete (Bernlef, 1988) and for the older partners of those with dementia the loss of a known personality even whilst they are still together physically may be one of the hardest things to bear. For some becoming old in an ageist society can be an experience of losing a sense of value and a sense of self.

The power of mental health professionals to define what is `mental illness' can be considered another structural feature affecting the identifies of those experiencing mental health problems. In his study of a large asylum in Northern Ireland, Lindsay Prior (1993) has demonstrated the way in which mental disorder can be seen to be constructed by the way in which mental health services are organised by professional groups. There are shifting and permeable boundaries around what is considered to constitute mental disorder which may have more to do with policy imperatives and inter-professional rivalry than with the personal experience of people with mental health problems. At any one time, the `management' of people experiencing emotional distress requires categorisation to fit the ordering of the service system:

> `..no two users suffer from exactly the same illness and all of those illnesses are categorised into different segments and they say this is what you're suffering from and they put a label on you: "you suffer from affective disorder; you suffer from schizophrenia; you suffer from one of the depressive illness; you're an alcoholic; you're a drug user". Everybody is labelled'.

Because people in distress are scared of losing any sort of help, or because they themselves are confused by or scared of what is happening to them they may go along with the explanation they are given of what is wrong with them. If later they come to question professional authority to define their problems, either individually or collectively, they may find themselves patronised, or worse, treated as unreasonable upstarts (Barnes and Wistow, 1994).

The above demonstrates that whilst the experience and impact of mental illness is very personal, there is considerable evidence concerning the structural factors associated with the identification and experience of mental distress, and that these can contribute to the `problem' of identity for people experiencing such distress. However, whilst social/ psychological; political/ economic; and environmental explanations of mental distress have been advanced by professionals as well as from within the user movement (e.g. Davey, 1994), there is little evidence that the mental health user movement bases its strategies on a `social model of mental illness' comparable with the social model of disability. We return to this issue in the conclusion.

3.   *Citizenship status*

People with mental distress may experience similar `object' status in relation to professionals as do disabled people, and they also share experiences of poverty and exclusion. However, there are particular exclusions from the status of citizenship which do not apply to other disabled people (although they do in some circumstances to people defined as `mentally impaired').

Being defined as `mentally incapacitated' can result in individuals being denied the status and identity of citizens in important respects. The civil rights of those who do not pass the legal test of capacity are constrained. For example, those considered incapable of managing their property or affairs may find that they have to apply to the Court of Protection before they can spend money belonging to them; contracts entered into by those subsequently considered to be mentally incapacitated at the time the contract was entered into may be declared invalid. Whilst such measures are designed to protect people from exploitation, they also clearly represent a significant constraint on basic citizenship rights. Such constraints are even more evident in the ineligibility of mentally incapacitated adults for jury service, and to vote. Decisions about the latter are made by the returning officer (Law Commission, 1995).

People diagnosed with a physical illness cannot be legally forced to enter hospital, nor to receive treatment in the interests of their health, unless it is

required in an emergency to save their lives. Those diagnosed as mentally disordered can be both forced to enter hospital and to receive treatment against their will. The potential for compulsory detention; for forced medical treatment; and supervision following discharge from hospital are all experiences which are particular to people considered to be mentally disordered. This has direct effects for those subject to the provisions of the Mental Health Act, and has a knock on effect for those who fear the possibility of being detained. Thus, not only can mental disorder affect people's personal and social identity, it can also affect people's identity as citizens.

HOW DO MENTAL HEALTH USER GROUPS RESPOND TO THE ISSUE OF IDENTITY?

In this section we consider the ways in which user groups may seek to respond to these different problems associated with the identity of people experiencing mental distress.

The three groups that we have worked with in our research illustrate some of the diversity amongst groups of people experiencing mental distress. We will describe them very briefly.

Group One is a long established organisation which aims `to promote the interests of users and ex-users of the psychiatric services (town)'. It is an umbrella group for a number of other groups, has a well developed advocacy service and is a broad church in terms of its response to specific issues. It has developed and continues to develop a relationship with both service providers and with users and ex-users, and aims to influence service provision both locally and nationally. It works on democratic lines, although formal membership is not necessary for people to participate within it. The group starts from people's own understandings of their mental health problems and does not adopt a `party line'. For example, if individuals want help to ensure that they receive a particular form of medication advocates will take that on. Personal experiences of distress and of service use provide the focus for wider action through collective advocacy in relation to services. The group has substantial contact with and involvement in local service planning forums. Personal support and empowerment of members through action within the group is a significant part of their purpose, although the group was not seen by activists primarily as a support group. The rights of the individual to exercise choice over their use of mental health services are considered important and the group will provide advocates to support people in appealing against compulsory hospital admission. Different projects have

developed under the umbrella of this group including one which focuses on the empowerment of people within society as a whole, rather than as users of mental health services.

Group Two is a small campaigning group of users and ex-users who work within the local MIND organisation. There is no membership as such, but the campaign group attempts to keep in contact with users of services through providing an information and advice line and through seeking views and involving people in specific campaigns in which they become engaged. An advocacy project based in a local hospital has been developed under this group's umbrella. Choice and individual rights are seen to be important, but the group does not provide collective support and empowerment through membership of the group itself. The group has had involvement in service planning, but at the time of our last contact some concern was being expressed about the effectiveness of relationships with health and social services.

Group Three is first and foremost a service run democratically by users, for users. The group campaigns only on an informal and individual level. It provides a drop-in facility aimed primarily at younger people with mental health problems. It offers an alternative place to go for those who have found statutory services unsympathetic. Within this largely unstructured environment different activities are organised depending on the skills and interests of the users at the time. If people want simply to come to have a coffee and be quiet they can do so, but if people want support and help in dealing with things like housing or benefit problems other users will help out with this. If people want to take on a particular role in managing the centre or organising activities they are encouraged to do so. One part of the building is designated as a women's space and women users organise their own activities as well as taking part in running the overall centre. The group accepts people at whatever stage they are at - people can come to the centre without becoming active within it, although there are rules about behaviour within the centre and there have been instances in which people have been asked to leave. There is a reluctance to become involved with statutory service providers or planners.

The three are very different examples of mental health user groups and provide different examples of the way in which the mental health user movement may help in addressing the problems of identity amongst people experiencing mental distress.

1.   *Personal and inter-personal*

Why do people become involved and what do they get out of being part of individual groups and, in some cases, the wider user movement?

By involving themselves in these groups a user or ex-user has to `come out' as someone who has experienced mental distress. Through their involvement, individuals have to be prepared to identify themselves in this way, even if only within the group itself. People also have to find value in being with other users of mental health services.

In this study we have been focusing on those who have become activists within the groups. For this group of activists the often negative experiences of mental distress and of service use have become a source of expertise and understanding which can confer credibility when representing that experience to service providers and planners, and which can enable them to provide support to users who may still be finding it difficult to speak up on their own behalf:

> `I think you've got an understanding, you know, if you have been through it yourself, you can help other people because you can understand what they feel like. If they're nervous you know why they're nervous and you give them time, you don't pass any judgements, make any comment on it'.

Whilst not all those we spoke to were happy to identify themselves as service users in all situations, in circumstances where they felt it was appropriate to help people identify with someone who has been through the same situation they will make public statements identifying themselves in this way.

In different ways the groups provide `safe environments' in which sometimes fragile identities can be supported, and confidence and skills can be developed and applied outside the group when the individual feels safe to do so. We heard many testimonies of the way in which involvement in the group had built personal confidence and which had enabled people to turn damaging experiences into a positive outcome:

> `In some ways it turned out to be a positive step for me. It changed my life around from something that was killing me, virtually, to something that I finally got some kind of reward in'.

> `..it's given me a life and without it I wouldn't have dreamed of doing half the things I do now. It's given me confidence, assurance... I get up now and speak at a conference quite happily. A few years ago I would

have no more done that than fly! So really we are here for ourselves as well as other people'.

For them, accepting an identity as a user or ex-user of mental health services and working with others who shared similar experiences had enabled them not only to provide valued support for others, but to find a valued sense of themselves:

`It makes you feel good... I mean everybody is accepted'.

Rather than being `ghettoised' in the user movement, the movement had enabled them to discover their own strengths. They also recognised the same process taking place for others:

`... there's quite a few that have come here and when they came they wouldn't say boo to a goose. They've been here a bit, you can't shut them up - which is what we want to hear'!

Participation within a group quite literally gives people a `voice' and as confidence develops people are often able to play a role in organising the group, in planning forums involving service purchasers and providers, and in representing the group at conferences and seminars. Acquiring new skills can provide a further boost to confidence and self-esteem and can also be a springboard to potential opportunities outside the movement:

`I believe in 3,4,5 years time maybe.... that will give me a chance then as an individual to join the mental health service as a professional, and I'll be able to take my experience forward with me'.

The groups accept the difference and sometimes difficult identities amongst those who become involved. For example, Group 3 was described as a `family' which allowed people `to be', rather than forcing them `to do'.

Others emphasised the `normality' of mental distress and the people who experience it and they saw a wider acceptance of this view as a role for the group:

`... a vicar's wife once said "what if I invite these people into my home? How would they be?" And I said "well they'll be like you, they'll have two eyes, a nose and a mouth and two ears". You know, they think they're going to see something weird and they don't know that perhaps they'll have a nervous breakdown and start with a mental illness'.

Nevertheless, whilst they are accepting of unusual behaviour which they recognise as a result of mental health difficulties, groups have rules about behaviour, for example in terms of the use of racist and sexist language, to ensure that positive rather than destructive inter-personal relationships can be encouraged.

User groups recognise that it may take some time for members to become active, and that some will never want to take on active roles. There is also a recognition that advocacy is based on acceptance of people's own understandings of their needs and that this may make it difficult for the group as a whole to adopt a particular stance on issues such as the use of particular forms of medication. This does not mean that they cannot advocate at a collective level for users to receive information which will enable them to make informed choices over what form of treatment they should receive.

2.   Structural

Addressing the structural inequalities which affect the identities of people with mental health problems is more problematic. User movements are more about agency than structure and there is little evidence of groups allying themselves with class based movements. The poverty experienced by many people with mental health problems can be addressed in part by individual advocacy in relation to welfare benefits entitlements, but none of the three groups we looked at were involved in broad ranging campaigns in this area. They may perhaps be better understood as examples of `new social movements' whose objectives are cultural and ideological rather than structural and material (Melucci, 1985). This was most evident in the work that had developed under the umbrella of Group 1 which was making links between environmental concerns and mental health issues and which sought to relate activity to improve the quality of life of people with mental health problems to broader issues of community and economic development.

One of the three groups we have been studying had tried unsuccessfully to engage with black groups but none had adopted an explicit race perspective within their work. On the other hand two had addressed the gender dimension within mental health: one by providing a separate women's space within the centre and one by very active participation in MIND's `Stress on Women' campaign. Within this group challenging people's perceptions of themselves and placing their difficulties within a wider context of societal expectations and economic circumstances was encouraged:

> `You see women, they're walking in here everyday of the week, you know, they're struggling with 3 kids at home, single parents and so on, and they think they've failed, you know, I mean, what man in a similar situation would succeed....'.

None of the groups had focused on the concerns of older people who had experienced mental health difficulties and indeed Group 3 was specifically aimed at younger people.

But it is also relevant to consider the role user movements play in addressing structural issues from a rather different perspective. Not only does the movement provide an opportunity for the collective empowerment of users through working together to address issues which are common to their experiences, participation in two of our groups illustrates very convincingly that people who have experienced mental distress are capable of participating in decision making structures with service providers:

> `One of the major roles that we can play is actually to say, we are users, we can participate at this level, we can articulate, we can challenge, we can negotiate, we can write papers, we can do this, instead of [being] some bumbling idiot that doesn't know what they are doing'.

Whilst none would claim that this has resulted in a fundamental shift in the balance of power within the mental health system, it has provided a challenge to the prevailing system and has forced those in existing positions of power to look at things in a different way. It has, in some circumstances, changed the nature of the relationship between providers and recipients of health and social care services, and has enabled users of those services to play a part in their definition and construction.

On a wider level, the groups that we have studied demonstrate that people who have used mental health services can be active agents, not only in controlling their own lives, but also in providing services to each other, and as participants within decision making networks, and this provides a challenge to public perceptions of people with mental health problems as incapable of rational thought or action. By running awareness raising campaigns which point to the commonality of mental distress and its links with the day to day experiences of large numbers of people, the casting of people experiencing mental distress as `other' becomes more difficult.

3.	*Citizenship*

We were surprised that civil rights issues did not feature highly on the agendas of these three groups. Involvement in campaigning for anti-discrimination legislation was not a high profile activity as it was in the case of disabled people's groups we studied. Nor was there much evidence of engagement in relation to the specific limitations on citizenship deriving from `mental incapacity'. Individuals were given support in making complaints and in appealing against detention under the Mental Health Act, but there was no evidence of active campaigning against the use of restrictive powers at a local level. Such issues are being taken up at a national and international level and it was suggested by some of those we spoke to that there was little point in attempting local action in response to issues which derive from legislation or national policy. Only a minority of users of mental health services are directly subject to the Mental Health Act or to restrictions arising from mental incapacity and thus it is likely that such issues are not such a high priority as concerns relating to services being received on a day to day basis. It may also be that the personal experiences of distress are so much more immediate than concern with more abstract notions of citizenship.

Nevertheless, a more general concern with individuals' rights to receive the services they need, and with issues of social justice in relation to people's lives as a whole were important aspects of the work in which the groups were engaged:

> `We are all unanimous that we want to have people with mental health problems to have much more say in their life in general, where they live, what medication - it's just the right to do as other people that are sound in mind, limb and body want, we want the same for people, you know, all of us'.

In some instances the motivation to become involved in user groups came from personal experiences of injustice or from having witnessed bad treatment of others within psychiatric hospitals. Advocacy was the method most often used to seek to achieve individual rights to services, whilst awareness raising amongst the general public were seen to be important ways of overcoming stigma and discrimination.

CONCLUSION

The anti-psychiatry movement of the 1960's suggested that mental illness was whatever those with authority to pronounce on `normal' or `deviant' behaviour might choose to make of it. Whilst the ideas of Szasz, Laing and

others associated with anti-psychiatry provided an important challenge to the medical model of mental illness and opened up the possibility of other ways of understanding behaviour defined as symptomatic of illness, those ideas have not been developed into an alternative model (equivalent to the social model of disability) which can provide the basis for both understanding the origin and nature of distress and providing enabling and empowering assistance to those experiencing such distress. The anti-psychiatry movement was never a direct expression of the experience of those with mental health problems, but was an analysis provided by intellectuals and professionals who would have been uncomfortable with the notion that their authority to define the origin and nature of problems might be challenged by those who were the subjects of their analysis. The only user group to share a similar stance to that of the anti-psychiatrists has been CAPO - the Campaign Against Psychiatric Oppression, whose membership has always been tiny (Rogers and Pilgrim, 1991).

There has been some attention from sociologists to the experience of mental health service users. For example, Rogers et al (1993) undertook a large scale survey of users' experiences; Prior (1995) has drawn on the work of Goffman to reassess the impact of institutionalisation on the identity of psychiatric patients; whilst Joan Busfield (1982) and Agnes Miles (1988) have brought a sociological perspective to bear on the issue of women's experience of distress and of the mental health system. But there has been little attempt to develop a `sociology of mental health' to equate with Mike Oliver's `sociology of disablement' (Oliver, 1990) and which draws on both the experiential knowledge of mental health service users as well as theoretical insights from within sociology.

A potentially useful sociological perspective which we are starting to apply in the context of the research on which this article is based is that of new social movement (NSM) theory (see e.g. Dalton and Kuechler, 1990; Scott, 1990; Touraine, 1985). Disability theorists (e.g. Oliver, 1990, Shakespeare, 1993) have applied NSM theory to disabled people's movements, but with the exception of Rogers and Pilgrim (1991) there has been little use of this body of work in relation to the mental health user movement.

Our research suggests that the factors which provide the strongest motivation to participate in mental health user groups are the shared experiences of distress and of being a recipient of mental health services - of being a `patient'. For many the values attached to participation are as much about the personal support and growth which can come from participation as about political or service developmental outcomes which can be achieved from collective action. In starting to apply NSM theories to the study of mental

health user groups we have found it necessary to distinguish between movements based on commitment to a cause, for example environmentalism, and those based on a shared identity, such as that of a user of mental health services. Identity based groups are concerned with personal experiences and responses to stigma, exclusion and disadvantage; with valuing devalued identities and experiences; and with building those personal experiences into a basis for collective action.

Thus it is important to understand and to theorise personal responses to mental distress in order to make the link between such experiences and collective action. The work of feminist psychologists, sociologists and political scientists can assist in this, but it may also be valuable, as Prior (1995) does, to draw on other theories of identity construction.

Since our research was not designed directly to address the relationship between personal identity and collective action, we can only speculate on this at this stage. Clearly, identity is important to those active in mental health user groups in all the dimensions discussed in this paper. Participation has provided a route through which the identity of passive recipient of services can be transformed into that of an active contributor to service development. Working with others with similar experiences has enabled activists to challenge the assumption of incompetence which often follows a diagnosis of mental illness, and to challenge the exclusions which can result from this. By no means all those involved in user groups reject the notion of `mental illness' or are totally opposed to the provision of medical treatment. The objectives of those who do consider mental illness to be a reality are to ensure truly `informed consent' to such treatment and to enable access to the information which will enable them to make choices about alternative types of treatment and to decide when and if to continue with what they are receiving. They also argue that being `mentally ill' does not mean that people are abnormal or even different - mental illness is something which anyone could experience at some stage of their lives and should be regarded as one aspect of the normal experience of being human. Thus the social, economic and civil rights of those experiencing mental distress should not be affected. However, they have not developed a strategic approach to addressing the structural and legal factors which do, in practice, mean that the position of people with mental health problems as citizens is affected.

Others do suggest that the concept of `illness' is wrongly or too widely applied. This leads to actions intended to secure alternative opportunities for rebuilding self confidence and self esteem, and for developing positive identities as citizens participating in the lives of their communities in ways that make sense to them. In some instances that also leads to an analysis of

the social, economic and environmental conditions necessary to support mental health for all.

At this stage in their history user groups still have to develop ways of ensuring that differences associated with gender, age, race and sexuality can be positively embraced within the movement. No-one we spoke to claimed that their experience of mental distress defined their total identity, nor would want it to, however much they valued the affirmation of themselves provided by working with others who had similar experiences.

The area in which the user movement has been most successful is in supporting the participation of people with mental health problems as active agents, capable not only of determining their own personal histories, but also in determining future directions for mental health services and in achieving broader cultural goals. In order to achieve this, user groups will need to continue to recognise the importance of responding to people's personal experiences of distress and of service use, alongside the development of collective strategies for achieving change.

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