Towards a social model of madness and distress?

Exploring what service users say

Peter Beresford,
Mary Nettle and
Rebecca Perring

November 2010

This report explores mental health service users' views about social approaches to madness and mental distress and their relationship with the social model of disability.

At a time when there is growing interest in 'recovery' in mental health policy and practice, service users highlight that a medical model still dominates public and professional understanding. They largely see this as damaging and unhelpful. They see social approaches to mental health issues as much more helpful. At the same time, their views about the social model of disability are complex. There is no consensus.

In the report, a wide range of service users look at:

• how mental health issues are understood in society;

• people's personal understandings of mental health issues;

• the social model of disability in relation to mental health;

• a possible social model of madness and distress.

Labelling and stigma following from a medical model of mental illness emerge as major barriers for mental health service users. The report highlights the importance of developing discussion about social approaches to mental health among service users, professionals, policy-makers and the public, to improve understanding, policy and practice.

JOSEPH ROWNTREE FOUNDATION

www.jrf.org.uk

Contents

Forewords

I was very excited when I first heard that this piece of work, led by mental health service users/survivors, was being undertaken. As far as I was concerned, it was long overdue.

This study is important for many reasons. It could be argued that the mental health service user/survivor movement and that of the wider disabled people's movement have been, and are, for the most part carving their own paths ahead. Also, in recent times, some key government documents that the disabled people's movement has helped shape seem to have passed mental health users/survivors by. If we as mental health service users/survivors joined forces more closely with our disability colleagues, we would help each other to influence the strategic debates, and make sure users/survivors don't miss out.

A crucial and defining factor in this project is that it is led by survivor researchers. This, to me, is the only way that service users/survivors can highlight what we consider important to ask. Moreover, the report uses many of the personal narratives given by those users/survivors and disabled people to help bring the issues to life, to the extent that it is actually co-written by those taking part. This is true power sharing.

The medical model is such a dominant way of viewing our lives that it does not allow for other discussion, and therefore consigns the 'ill' person to a negative outlook on life, which is mirrored by society's reaction to us. We will contend that how conditions – those that we have, or those that surround us – affect us is far more complex than how the medical model expresses it. Views on this can be found within this report.

Also, there is no consensus around the terminology of what we or others call us. Language is contextual and can be very powerful in how it is used. Why is so much of the mainstream language to describe disability and mental ill health so negative, when it could be so liberating?

I hope that this research helps to bring the mental health user/survivor movement closer together with our disability colleagues. We have so much in common, often sadly through the oppression we all experience. However, we also have much to learn from one another in the form of user-led ideas, campaigns and successful projects that help shape a brighter future for us all.

There is still much work to do, but this report helps light a fire under the debate that needs to crackle and roar, and I suspect will not go out for some while yet. We all have a collective responsibility to move forward the ideas and recommendations within the report, and I look forward to working with you on them.

Tina Coldham
Chair, National Survivor User Network
www.nsun.org.uk

Since its formulation in the early 1980s, the social model of disability has had a considerable impact on public policy, disability politics and disabled people's own understandings of their positions in society. It has also provoked considerable controversy and conflict over its appropriateness and application. This has resulted in it being stretched beyond the parameters of its initial formulation, which was as a tool for producing social change, into a comprehensive explanation for the disabling society. As a consequence, in recent years too much time has been spent in heated academic and personal debates about its relevance and usefulness and not enough in applying it to the real life circumstances of disabled people.

This report is therefore to be welcomed because it takes seriously the need to examine the social model's usefulness based on lived experience and does not regurgitate yet more arguments about the need to abandon or modify it. In asking pertinent questions about how it might be used to change the lives of a group of people who use mental health services, it goes into an area where little work has been done so far. In so doing it raises the controversial question of where impairment fits into the social model; it also demonstrates that most of the people interviewed brought with them a social understanding of their own circumstances and that for a considerable number of these participants this had been informed by the social model of disability.

The key dilemma the report raises is whether a distinct and separate model of madness and distress is needed or whether the issues and concerns of mental health service users can be incorporated and utilised within the social model of disability. Clearly, this is a key issue for the politics of mental health in particular and disability politics more generally. All those who continue to talk about the social model rather than use it would do well to read this report, as it shines as a beacon for further attempts to generate social change.

Mike Oliver
Emeritus Professor of Disability Studies
University of Greenwich

List of tables

Tables

Executive summary

This report offers the findings from a two-year user-controlled national study exploring the idea of a social model of madness and distress and its relationship with the social model of disability. It is primarily based on the views of a wide range of mental health service users. Four key issues were explored with participants:

1. How mental health issues are understood in society.

2. Their personal understandings of mental health issues.

3. The social model of disability in relation to mental health.

4. Their personal understandings of madness and distress within a social model of disability.

A number of key findings emerge from the project. These include that:

- There is significant agreement that the existing dominant medicalised individual model of mental illness is negative in effect;

- This medical model is seen as very powerful among professionals, in society generally and also among service users, shaping understanding and attitudes;

- Service users' views about the social model of disability (with which most were familiar) are complex and varied;

- At the same time there is strong support for more social approaches to understanding and responding to 'mental health issues'. People feel that broader issues need to be taken more account of to counter the individualisation of mental health issues;

- Most participants feel that, as mental health service users, they experience barriers in the same way that disabled people have highlighted the barriers restricting them;

- There is no consensus about terminology in this field among service users. This relates to the negative associations of most of the terminology in use. This creates significant barriers and problems in the way of advancing thinking and action towards different understandings of mental health issues. These should not, however, be seen as an insuperable obstacle, as a lively and diverse service user/survivor movement has developed;

- Some service users can see real gains in developing new ways of thinking about mental health issues, building on a social model of disability. They see this as encouraging greater unity and shared understanding among different groups of service users and a conceptual framework more suited to valued approaches to personal and social support;

- However, some service users also offer challenges to some existing understandings of a social model of disability and some other service users see the framework of a social model of disability as less helpful;

- A particular issue that creates concerns for people is the concept of 'impairment' as part of the social model of disability. Some mental health service users feel that they and other mental health service users may not have an impairment and that it may therefore be unhelpful to apply this idea to them;

- This prompted some service users to think that more thought was needed about the social model of disability, a possible social model of madness and distress and the relation there might be between the two.

These findings provide the basis for a series of recommendations, which are mainly concerned with sharing and developing discussion around social understandings of mental health issues that will help in taking forward the current emphasis on advancing independent living and a rights-based approach to increasing the life chances of all disabled people, including mental health service users. The report's recommendations include:

- sharing the findings of this project more widely among mental health service users/survivors, disabled people and the wider disabled people's movement;

- facilitating further opportunities for mental health service users and their organisations to discuss these findings and explore their implications;

- sharing the findings from this project with the Social Perspectives Network as a basis for follow-up action;

- from such discussions identifying priorities for action, particularly in relation to the negative effects associated with current dominating medical models of mental health issues and the negative media presentation of mental health matters;

- setting up an ongoing group, or linking with a suitable existing group, of mental health service users to take forward discussion on the social model of disability in relation to mental health service users and the further development of a possible social model of madness and distress;

- for existing proponents of the social model of disability to explore how it might be more accessible, particularly for mental health service users, so that they are able to gain a better understanding of it in relation to themselves;

- for survivor leaders and activists, particularly those concerned with the movement's value base and philosophy, to explore the social model of disability in more depth, considering whether and how it might be developed better to address and include mental health issues;

- providing opportunities for mental health service users to become more aware of disability issues generally and the social model of disability specifically, and how these might be relevant to them;

- supporting mental health service users/survivors and their organisations to learn more about the work of the disabled people's movement and legislation/rights issues that they can benefit from. This will help them to secure rights and work together with disabled people's groups on common issues, such as direct payments, individual budgets, personalisation and self-directed support;

- undertaking a parallel examination to that reported here of service users' views, exploring mental health workers' views of social approaches to mental health, any differences there may be between them and particularly the relevance of the social model of disability;

- providing increased opportunities for mental health workers, particularly psychiatrists in qualifying and other training, to become more familiar with social approaches to mental health issues and specifically the social model of disability;

- creating more opportunities for different groups of service users to come together and explore ideas like the social model and Independent Living together, thinking through possible similarities and differences. Shaping our Lives, the national user-controlled organisation and network, works across different user groups and finds this a helpful way of breaking down barriers and sharing understandings and experience.

Labelling and stigma emerge again in this project as a major barrier for mental health service users. Some, however, have begun to challenge negative labels and identities imposed on them. It will be helpful to explore how mental health service users might be able to challenge the negatives attached to them and take greater pride in who they are, possibly reclaiming language which has been attached to them for negative and hostile reasons.

Introduction

This short report offers an initial account of the key findings from a two-year national project exploring the idea of a social model of madness and distress and its relationship with the social model of disability. Two crucial concerns of the project were: first, to encourage discussion about a social model of madness and distress, particularly among mental health service users/survivors and their organisations; and second, to indicate areas for further research and development, at a time when there has been growing recognition of the importance of a rights-based approach to mental health service users but their rights have been subjected to increased legal restrictions, notably through a new Mental Health Act.

Medicalised individual models of 'mental illness' continue to predominate in the policy, practice and analysis of madness and mental distress, even though they have been subjected to challenges from both professionals and service users over the last thirty years. Based on psychiatric categories of mental illness and disorder, mental health practice and policy has primarily been associated with individual treatment responses, particularly based on drug therapy. The mental health service users'/survivors' movement, however, has not as yet developed an equivalent to the social model of disability, although some survivors seem to reject the medical model of 'mental illness'.

The social model of disability was developed by the disabled people's movement. It challenged traditional understandings of disability. These focused on the individual, seeing disability as located within individual disabled people and resulting from some inherited or acquired disability which restricted what disabled people could do and might result in them being dependent and unable to live a 'normal' life. During the twentieth century, such individualised understandings of disability were overlaid by the medicalised thinking of emerging medical professions, which appropriated disability as an area of their expertise. The disabled people's movement saw this as resulting in a medicalised individual model of disability which conceived of disability as pathological and disabled people as requiring institutionalisation, rehabilitation and welfare support.

The social model of disability which disabled activists developed drew a distinction between the physical, sensory or intellectual impairment or perceived impairment affecting an individual disabled person and the negative societal reaction to it, which they conceived of as disability. Thus disability was understood as a discriminatory and oppressive response to people seen as having an impairment, rather than a characteristic attached to the individual. For disabled people, this has been a groundbreaking idea, shifting blame and responsibility for disability from the individual to the society.

The purpose of this project was to explore whether the social model of disability or some equivalent 'social model of madness and distress', building on it, might offer a helpful alternative conceptual framework for mental health issues.

There has been an increasing interest in social approaches to mental health in recent years, reflected, for example, in the establishment of the Social Perspectives Network, whose work has involved service users and survivors as well as allies, and the production of related publications (Tew, 2005; Tew, *et al.*, 2006). There have been some initial discussions about a social model relating to mental health among mental health service users/survivors and some initial publications (Beresford, 2002; 2004). However, as yet this has not been widely explored or developed. The aim of this project is to try to open up this discussion and take it forward.

We sought to explore four main issues with participants in the project:

1. How mental health issues are understood in society.

2. Their personal understandings of mental health issues.

3. The social model of disability in relation to mental health.

4. Their personal understandings of madness and distress within a social model of disability.

How we carried out the project

We sought to involve three groups of people in this project to explore the issues that concerned us. These were:

- people with experience as mental health service users;

- people who identified as disabled people (people with physical and sensory impairments and people with learning difficulties);

- people who identified both as mental health service users and disabled people (with physical, sensory and other impairments).

In this way we hoped to get the broadest relevant range of insights possible regarding service user understandings of mental health issues, of the social model of disability and of a possible social model of madness and distress, drawing on a social model framework. Most participants fell into the first two groups, but we thought it would be helpful to speak to others whose experience was as disabled people, because of the insights they would be likely to bring to the project through their familiarity with the social model of disability. Mental health service users/survivors who were also disabled people could bring an experience and appreciation of both issues.

Participants included a very wide range of mental health service users and disabled people, although we are aware that the number of young people was limited. They included people involved in service user groups as well as those who were not, with a broad range of views and experience.

This national project adopted a user-controlled research approach. It was undertaken by two survivor researchers, Peter Beresford and Mary Nettle, based at Brunel University's Centre for Citizen Involvement, supported by a third non-service user researcher, Rebecca Perring. Peter and Mary have a background of active involvement in the psychiatric system survivors' movement and in undertaking user-led and user-controlled research. A total of 51 people took part, through four group discussions and 17 individual interviews. A diverse range of service users was included. A more detailed account of the way in which the project was undertaken is provided in Appendix 1. A copy of the schedule used for carrying out the individual interviews and group discussions is included in Appendix 2.

How this report is organised

This report is organised in five main sections. The first four reflect the issues that we explored with participants. All four draw heavily on the comments of service users who took part in the project. Their quotations make up the greater part of the report, in keeping with its commitment to being service user-led.

The four sections are:

1. How mental health issues are understood in society.

2. People's personal understandings of mental health issues.

3. The social model of disability in relation to mental health.

4. Exploring a social model of madness and distress.

This is followed by a final section which summarises the findings from the project and offers a set of possible ways of taking them forward.

There are two appendices. The first sets out in more detail how the project was carried out and the second provides a copy of the schedule that was the basis for both the individual interviews and group discussions that were carried out. Finally we provide a list of references and other reading material.

1 How mental health issues are understood in society

The general consensus of participants was that mental health issues are poorly understood in society. They felt these issues are associated with fear and danger. This association with fear and danger was seen to originate from and be underpinned by a medicalised individual model of mental illness. Such a medicalised approach to understanding mental health issues was seen as having few benefits to offer and largely negative in effect.

The few benefits identified by participants included access to welfare benefits and to medication, although the latter was frequently seen as compromised by the over-reliance placed on it in the psychiatric system:

> **I think you have to recognise that there are advantages to medical understandings … I mean I think for some individuals to actually be told that their problems are medical can be helpful. It can seem like a rational explanation, a scientific explanation. OK you've got these problems but here are a range of experts who can deal with the problems, that people may feel that blame, and all the rest of it is taken away.**

> **… I mean it's very easy to think that the social model is the best and the medical model isn't, but we all need the medical model in order to get our rights and entitlement. We need our diagnosis in order to get our rights and entitlements. There is still a place in society for the medical model – you just have to fit it in within the social model realms as well. So I think that drugs do have a part to play, but they're not the only thing that help make people and keep people well.**

> **'I think there are, definitely are, benefits because … the only time I will publicly admit to a medical model understanding is if [I] was needing some time away from work … now I've got a permanent job, and I might want to take some time off at some point, in which case I guess some kind of medical certificate could be very useful.**

> **… But with mental health you go and see your GP and you'll get anti-depressant. OK, it might help you a little bit but it doesn't actually look at what's causing all the problems, they don't look at all that. They have to go back to that and the physical problem, what's going on with the physical problems, but they don't look at the problems with mental health, what's causing it, it's sort of like medication, take that and you'll get better, well you're not going to get better by just taking medication.**

Much more often mentioned were the negative aspects that people associated with the medical model of mental illness:

> **… the problems I think it creates is that it's a predominately negative way of looking at people's lives, to think in terms of illness … it focuses on the individual rather than the situation in which the individual's living. It tends to apologise … it individualises problems,**

but it tends to make people feel negative I think, about themselves … and it doesn't actually remove the blame … the blaming aspect.

I'm not sure that I do see any benefits to that model because actually what I think that model does is blame the individual, the word in use, doesn't it. So it puts all of the blame on to you, there's something wrong with you, that's the message that you get, and the role that society plays, well, nobody thinks about that in that model, yet I would say society also plays a role in our individual experience because we're part of society. But the medical model completely ignores that and it's all about you are the problem.

… in a negative sense. I think people see them as something to be ashamed of, as a weakness of character … people still look very much as perhaps a medical thing; as something genetic that you inherit, and therefore there's something wrong with you … a weakness in the family line … and that it's something to be afraid of.

I think they are mainly understood as something to be feared, to be kept a distance from, very much associated with violence, either towards oneself or other people, but particularly towards other people.

I think there's a stigma … isn't there, attached to a mental health difficulty in society … I think it's the one thing that is still very stigmatised and people make all sorts of assumptions about people who've got mental health problems.

Most people felt that the media reflected and reinforced the lack of understanding of mental health matters which they saw as commonplace in society:

I think they [the public] are very influenced by the media stereotype, rather hysterical … someone jumped into the lions' cage at London Zoo and somebody with, I don't know … schizophrenia killed somebody, you know, the things that are actually very rare but are the ones that [are then used] to highlight the mental health issues in the media, but they always tend to be very negative, that's my experience.

The only time you ever hear about schizophrenia on the television is when someone on the news is murdered by a paranoid schizophrenic, and people tend to think that anybody with schizophrenia is [the same] …

… it gives a false picture in a way … there's a whole range of mental health issues.

Professional approaches to mental health issues were also seen as being mainly medically based, seeing the problem as lying within the individual and responding primarily through the use of medication. Such professional interpretations were felt to have an important and unhelpful influence on public understanding:

It's a deficit deviant model, that there is definitely something wrong with the individual … it's definitely a biological perspective, they don't see it as a social issue, it's a biological thing full stop. And they respond by giving you drugs, giving you electric treatments, whatever they call it, that kind of stuff. It's an individualistic approach.

… definitely a medical model, for professional thinking that even … I mean even so-called social care get sucked into that way of thinking, the medical model, you know, it's predominant.

Well, I mean it completely … the medical model … I mean it identifies, you know, what's wrong with this person's brain, why are they acting in this way, let's fix it. so it's completely underpinned by a medical model by both professionals and political models.

I think GPs know very little about mental health issues and will often prescribe medication when perhaps in some instances counselling and someone to listen to would be a greater assistance to the person.

Well I think [public understanding is] undoubtedly going to be dominated by professional understandings, because in the main ideas around mental health problems and mental illness, or the idea of, I think isn't understood by a lot of people unless they've had personal involvement or experience with it. So it's something that people fear, and I think when we fear things we tend to look towards people we think might know about those things and for most people that is going to be the professional experts.

While this study did not make it possible to differentiate between the approaches of different professionals, for example, between psychiatrists, social workers, nurses and psychologists, where differences might be expected, it did suggest that service users saw medicalised understandings as still predominating in professional approaches to mental health issues.

Participants felt that a good understanding of mental health issues tends only to come when people have personal experience of madness and distress, either in their own lives or the lives of those close to them:

I think a lot of people have a much better understanding of it, because it is very common and in my experience people know people, people have people in their families, etc., etc., or they themselves had used mental health services …

My mother did not understand it at all, she had no mental health problems at all. The rest of my family, my brothers and their wives have some understanding because they have mental health issues themselves and I do think that you do get a better understanding from people who have had problems themselves.

As the following exchange illustrates, some participants felt that the lack of such direct experience and understanding was a key issue which created problems for policy-making:

… and when it comes to the mental health policies, I mean I know a lot of these big decisions are made in, is it Whitehall they're at?

Yeah that's right, government level.

I actually wonder how many of these people truly understand what it is like, I mean, yes, they have a masters in something or other … But it's true though isn't it, so I think what happens is you are classed as the academic because you can do this … but do they truly have an interest, and have they read up, or have they actually met service users, or actually gone to ground level and gone to some of the hospitals in GPs' surgeries, and I think that is part of the problem as well.

But that's politics through and through isn't it?

2 People's personal understandings of mental health issues

Most participants felt that mental health problems were a complex issue, affecting people in different ways. They mainly felt that their understanding of mental health issues fitted within a social approach and they found this helpful. A common view was that mental health was affected by and a response to broader social and environmental factors. These could have a short- or long-term effect. They located the individual's experience within their broader social context, rather than thinking it could be understood in isolation. They felt that there was no one way of understanding mental health issues because of the range of different problems and issues that could affect people in different ways:

> **A lot of mental health issues are related to our experiences in life and those might be childhood experience or experiences of growing up, also risk and resilience that might have been a part of our family experience growing up … I very definitely believe it as being something very complex and … not something that's easy to … describe in a way. So there are lots of different factors and we need lots of different ways of dealing with those factors, those issues that come up for us. It doesn't make it easy to deal with in many ways, but I definitely believe in things being quite a mixture of different things.**

> **If I was to define mental health issues, then I'd describe them as … there are mental health issues that are emotional, and [there] I am thinking about anxiety and depression and that kind of thing that are quite common. There's also stuff to do with difficulties and differences around perceptions of the world … If I had a model or framework it would be much more about … I suppose it's a kind of more social model approach, it's taking on board these cultural views of mental health, these policies, governments, individuals, how people feel about it themselves, how they're treated by their families, jobs, I think it's all so tied up.**

> **I understand mental health as essentially the outcome of a personal and social relation between an individual and her/his environment (physical/spiritual/social/cultural) over time.**

> **There are various systems of oppression that can result in psychological distress depending on a person's political and social location.**

> **The solution becomes not medication or electric shock but a change in the norm of social relationship. So for example that children have more power, that men and women have more equal relationships rather than having the husband beating up on the wife, right.**

> **… I think more of a social [approach]. I think pressure comes from society and pressure comes from what's actually happening in your life.**

Participants felt that a social approach to mental health issues brought with it a number of benefits. It was likely to lead to better understanding, better personal support and a service user focus in provision, and could help change and improve wider attitudes by challenging narrow medicalised understandings of mental health. On the other hand, some potential problems with such a social approach were also identified. It might be difficult for people to understand and implement in a society strongly rooted in a medicalised individual model of mental illness:

> **Without this way of thinking and understanding we are not receiving appropriate support with our mental health issues, we are not able to say clearly what aspects of our society should be challenged as damaging to emotional and mental health [and] preventing us from fully engaging within it.**

> **I think that any approach that actually broadens out people's understanding of what's going on I think is a movement in the right direction, because I think that for a long time you're stuck in this looking at people as individuals, looking at people's problems in terms, if you like, of malfunctioning as a mechanism, so I think that anything that moves away from that is helpful.**

> **It is about the whole person, it's about that person and what happens to them, but the social in terms of, you know … things happen to people, you know, that they don't have any control over and become victims and therefore we have to take those things into account really … it isn't just something that happens within the individual, you can't place it all within the individual when you look … get to understand why people become unwell, and then you listen to them and you think 'well why not', because they've had all sorts of losses, in terms of bereavements and job losses and job roles and role offers and various things go on, and you know, a lot of it is completely out of their control, and yeah that's the only way that they could react that isn't perhaps, you know, the best way but that's what happens to people.**

> **Would the medical professionals have a hope in hell of knowing how to use it? It would be nice if they could and some do, but generally speaking it's like people think in boxes and they … they find it quite difficult to see the person in context.**

> **We are so steeped in our understanding from a medical perspective that it's going to create problems, I would imagine, between patients and professionals, you know, if we understand ourselves in a certain way that we, you know, are forced to go and see psychiatrists who understand us in a completely different way then there is going to be conflicts.**

A number of factors or requirements were identified if such a social approach to mental health issues was to be successful. It would need to take account of people's individual and different needs as well as shared social circumstances and barriers. Then it could link well with complementary and alternative non-medicalised therapies valued by service users. It would work best coupled with improved mental health awareness through appropriate education programmes for professionals, children and the public. Professionals would need to work more closely with service users to develop a better system for supporting them. Such a social approach would also be more consistent with service users having control over the support they received and the development of user-controlled support services. It also chimes well with government and broader political commitments to extend the use of direct payments and individual or personal budgets, to increase 'choice and control', both in social care and in the National Health Service.

Finally, more funding would probably be needed to provide better quality and a wider range of support services for people and to challenge existing barriers restricting people's access to support:

The important element in a lot of these approaches is to actually respect the expertise, experience and insight of the individual you're trying to support and how do you actually do that? I think that's a difficult one, but I think that it's an overall question about all models – how do you accommodate individuals?

Well, obviously it needs to take into account discrimination and prejudice. Be treated as an individual. You gotta be treated with respect. We're not round the bend, we're not mad, we're people, and we just need help out there.

An holistic and social approach will need to overcome the lack of public understanding/ sympathy/patience for mental health difficulties – perhaps because some people see them as a weakness they themselves avoided or overcome, or as our failure to accept society as it is and 'make the most of it' or as a somewhat horrifying illness beyond comprehension … ? We are generally seen (even by ourselves?) as being at fault – 'not coping', 'not fitting in' of 'holding strange views' or 'behaving oddly'.

I think people really need to have an understanding of mental health issues. That's why I think it should be taught at schools because … there are so many things going on in your life when you are older … that you are not so receptive. A lot of the time it is that people say that there isn't time. And one of the things that people do need to give is time.

The only way is to educate.

It's annoying when you come up with a good idea and you don't even see them try to start it. X and I go to partnership board and have been on committees that have even got renamed since, but the new name's too long to even say. And they whinge on about psychology. 'No. You can't have psychology, you're not frightening enough, dangerous enough', I didn't have it for eight years. I don't even like one-to-one treatment, it's confrontational, it's … you banged up in a room with someone opposite to you, who apparently maybe knows all the answers, and … group therapy works better, there's a syllabus, it's not as content based, it's not as intimidating …

I think [my preference is] towards a more user led and user supported stance because I still believe by sitting here in a room with people and discussing things and understanding what's going on is gonna do far more than medication. Use medication if you have to because I still do to get some sleep, [but] …

See I think you just need more community groups and groups like this where you can go and get a cuppa tea and sit down and talk to people … people that take time.

People's personal understandings of mental health issues

3 The social model of disability in relation to mental health

Most participants in this project were familiar with the social model of disability. The social model is a dynamic and developing idea about which there is continuing controversy and ongoing discussion (Thomas, 2007). Participants understood the distinction it draws between individual impairment and disability and its identification of disabling barriers in society which exclude and discriminate against people with impairments. However, there was no agreement about whether it related helpfully to mental health issues. Participants were divided in their views. The social model raised conflicting and contradictory views. Some identified benefits; for example, removing individual blame from mental health service users, and the inclusive nature of the model:

> **To me the social model of disability says that the problems that disabled people face are to do with two main things – one, if you like, is people's impairments, people's intrinsic problems, whether it's a sensory impairment, a mobility impairment, mental impairment – and [two is] society's response to that impairment. And that the most important element to that quite often is society's response to people's impairment. So, when we're talking about disability, disability is not the same thing as impairment; disability is about the overall social response to people's impairment.**

> **I think that the social model of disability means that rather than locating problems or difficulties in individual deficit or what is wrong with people, disability is viewed as something which is external to the individual, and is often thought of in terms of barriers, so barriers to inclusion in the mainstream. There's maybe physical barriers, there may be social attitudes and political … I don't think the social model is exclusionary of any particular groups of people. Ideas about mental illness, and ideas about learning difficulty are not defined by the individual. They are defined by society. You're labelled in a certain way and society responds and one way or another we all internalise that. Whether we accept it willingly, and turn it on its head as political issues, as something that is a different issue, but whether you like it or not, if you're seen to have any kind of impairment, you will be labelled and treated in a certain way, and that will affect your behaviour.**

> **I think in terms of the social elements of the social model of disability – the societal response element, I think that that is fine by and large, and I think there is lots of common ground there.**

> **The social model of disability helps in the understanding of mental health issues in so far as it challenges a previously dominant medical model, places emphasis on a social and political context, highlights experiences of discrimination and exclusion.**

Other participants rejected the social model because of its association with disability and the feeling that identifying as disabled would add to the stigma they experienced and imply that their devalued status was

permanent (although, of course, some impairments are intermittent or fluctuating in nature). They felt that disability and mental health issues were different and should be kept separate:

> I mean it's a framework to be able to describe society and what it does is instead of placing the problem with the person, it places the problem in society, with … for wheelchair users, it is having a wheelchair and ramps to be able to get into buildings so that they can use those facilities. It's a bit complicated for mental health service users, I'm not sure I've done enough thinking about that.

> I think instinctively, at a gut level I've felt 'no, my mental health problems are not an impairment', I don't see that they are an impairment for a range of reasons. So I think that's a limitation in the way I understand the social model of disability at the moment, I don't actually feel that the impairment bit accommodates my experience.

> … I'm not sure I wanna be called disabled.

> I think there's a disabled input in different ways like when you say you see someone physically you know – you stand away whereas societies see someone with mental health [problems], they shy away as well, even to the extent of lock 'em up – I don't know whether they quite do that with disabled people! But with mental health – it's lock 'em up!

> The problem with [associating it with] disability is once again the fact that it is making it seem to be permanent and irrecoverable, that's what I don't like about it. It certainly should help people making policies more careful about how they're structured and, you know, help people to become more included, but the basic idea that there is something permanently wrong with you I don't like at all, or that you're inadequate in some way.

While some people felt that the social model of disability could be helpful, there was also a strong sense that the medical model was so strongly ingrained in society that it would be difficult to change people's perceptions, both as members of the public and as service users who had come to internalise the medical model. At the same time all participants felt that mental health service users experienced oppression, legal and other restrictions to their rights and other barriers:

> Yes [we experience oppression and barriers] to jobs.

> Insurance.

> Or to be on jury service.

> We get oppression from the A and E [Accident and Emergency] department and the police. You're treated like a drunk or a druggie, you know when you're picked up, when you're ill or something. There's no kindness.

4 Exploring a social model of madness and distress

When we focused on a possible social model of madness and distress, it became clear that there was no common view. Some common themes emerged, but there were also contradictions in what people said and some strong disagreements. But discussion about such a social model, related to the social model of disability, was qualified from the start by the lack of any consensus about language which would make it possible for there to be shared common ground over any alternative terminology that was not based on a medical model. This inhibited discussion about alternative approaches to mental health issues.

Problems of terminology

'Madness' and 'distress' are terms which have been used by some survivors and survivor activists to challenge the medicalised nature of mental health discussion and policy. This was highlighted by the establishment of Mad Pride, an independent survivor-controlled organisation and network. We first asked participants how they felt about these terms personally and then how they felt the terms were understood more generally in society.

The strongest personal reactions were to the words 'mad' and 'madness'. Some participants valued the terms. They felt that they conveyed experience in terms which people could relate to. 'Madness' was a word that could be helpful to describe periods of extreme distress:

> **I know a lot of people who are trying to reclaim that word, to own it and therefore to take the stigma away from it. And I know within the women's movement that's happened that women have reclaimed words and used them positively as a way of stopping other people using them in a derogatory way. I think it's very positive actually, I think they should have pride in the work they are doing … I think it's challenging isn't it to society.**

> **Well [the terms] are nice and clear.**

> **Yes, but [the word mad] does describe certain things that happen to people. I don't agree with using it for a label, to say that somebody is mad. But if you use the word mad in amongst a group of people who haven't all experienced mental health problems, they might begin to understand what actually does happen to somebody who is having these problems, because in the first place they might be able to see in what ways it might be similar to their own experience.**

> **Well I like distress because I think that really does capture what I experience, and also sometimes I do feel quite mad, I do feel mad; I mean it is quite a good word to explain how I feel.**

Other participants were not comfortable personally with the term 'madness':

Yes, it's just that the term … I don't agree with the word madness.

I stick to my guns and I don't like the word madness. I think it ought to be done away with.

It's a negative.

It's labelling and stigmatising.

Broader understandings of madness in society were still associated with a medical model which pathologised people, so for a number of participants, the term did not offer the basis of an alternative understanding, but rather another negative way of expressing medicalised individual thinking. Broader understandings of madness were thought to be negatively influenced by the media. Both madness and distress were felt by some participants to be seen as a sign of weakness in society:

But they are distressing to some people I think because of the way that madness is viewed and the word has connotation, and violence and craziness.

I think madness means you're bonkers and you should be locked away on the funny farm and I think that distress is something that they would identify with themselves.

I think if you talk about distress you are talking about someone who is weak, I think that perhaps the general public, um, then think that it is a sign of weakness and that if you're, if you're strong and if you do get distressed you should be able to pull yourself out of it!

[It takes us back to] talking about the mental asylums that used to be. The mad house that they used to be called.

But I think, I find it difficult to answer that question on madness and distress. I don't have any problem with it, I don't you know, I think the word madness is a difficult word because of the way in which it's used, its sort of historical meaning if you like.

And I think some people, who would like to say mad is a good word let's accept it, other people don't think about it.

I don't really … I wouldn't expect that people who are, well, I don't know; I wouldn't want to know them either like. Unless you can come up with a new word that fits in with the model and criteria like, I think that using words like mad and crazy however should be outlawed and shouldn't be allowed to be said again like. Because it's exactly that, they envisage, visions of pain and suffering and violence and that's what you envisage mad means.

I think generally society thinks madness is a condition, some kind of mental deficiency of some sort. Distress, again I think they probably think of it as less severe issue. But as I say I think it can be severe issues, but I don't think it's seen as a severe issue.

I don't think society understands that at all. It is something they see on TV, in films, like a Jekyll and Hyde – it is something to be afraid of.

Exploring a social model of madness and distress

Stereotypical madness is 'eeeee', you know the score, right. Most people's idea of madness is, isn't it, is the old Hitchcock film, you know, it's quite mad like. That's often how people refer to it.

Most people felt that the term 'distress' was more helpful than 'madness' (although it could be trivialised), as one which people could more readily relate to because distress is something that anyone can experience. But it was still not a straightforward term for everyone and some people rejected it:

I think everybody's distressed, I think it's a preferable term to madness obviously, but I think distress is a much more acceptable one, because, you know, it's a common experience, you know, I mean the line between what is mental illness and isn't I think is really fine, and I'm going back to issues around stress – we all experience stress at some point, and at some point we, you know, all potentially get to breaking point where we can't cope, you know, and some of us can deal with that and others can't, you know, it's understandable and it's a common experience. I don't see why those who experience extreme distress should be labelled and treated any differently else. If that makes sense.

Being distressed isn't the same as the madness we were just talking about because distress to me simply means that you feel unhappy because people are so miserable and unkind, uncaring, and unthoughtful and really, really unintelligent and stupid and that distresses you, that very fact distresses you and you feel distress. I think that's how I see distress.

Madness is a derogatory statement and distress is something that everybody feels. So, if they're trying to say that the level of distress that you have when you're having a mental illness is the same as somebody's distress when their boyfriend leaves them or their girlfriend leaves them, or you know, when you lose a job, well fine, use distress … But I think it's to a degree that it needs to be differentiated from the normal range of distress.

Well distress is quite a useful term because it can kind of cover quite a few diagnoses I suppose and it can quite successfully describe how someone might feel. I'm not all that keen on 'madness', particularly, I think, because of the connotations of how it was used in the past really.

At the same time there was a strong and widely expressed feeling that there was a need to move beyond an 'illness' model of 'mental health issues' and a need to understand their social relations and to stop focusing narrowly on individualised responses and 'solutions':

I quite like them actually because it de-medicalises it. And I think it actually offers a much better description because the idea for me of somebody having, for example, distress and it kind of normalises it a bit, as if to say, well this could happen to you too. Particularly, I mean, if somebody has a breakdown, for example, or actually acute psychological distress [for that to] mean a passing phase – you can get better. There's hope and containment if you like. Whereas mental illness almost implies, well that is it. You're written off.

Lack of agreement about terminology can be expected to create barriers in the way of advancing shared thinking and action. But it is also interesting to note that this does not seem to have prevented the development of a lively service user/survivor movement in mental health which has enough space for a diversity of views of people's issues to be embraced and sometimes argued over.

A social model of madness and distress

There was a feeling among some participants that there was a real need for such a social model of madness and distress. While the terminology of 'madness and distress' was an obstacle for some people trying to think about a social model, they highlighted in their comments some of the benefits they could see it bringing and issues that it needed to address:

> **Yes, definitely, definitely think it could be helpful. I mean we definitely need to take into account the range of issues that form the problems that we have, and I don't think we can do that just on the basis of a simple medical model. And I think actually that a lot of people who work with the medical model know that actually, because otherwise they do research on other things. I think really they are recognising that there is more to it than that very often.**

One of the strengths seen for such a model was that it would help create solidarity and shared understandings between different user groups and improve the chances for joint campaigning. If more service user groups drew on such a social model, then it would be likely to be stronger and opportunities for collaboration would be increased. It could also help highlight the links between different people's distress and make clearer how individual distress might be associated with broader oppression and discrimination. There was also some sense that there needed to be recognition that the barriers that mental health service users face may sometimes be different from, as well as similar to, those which people with physical, sensory and intellectual impairments face:

> **The more people who identify with a social model, whether it be physically impaired, visually impaired, mentally … strengthens it, all the time. It's a collective idea and if more people identify with it the stronger it becomes.**

> **I think in the same way for with people with learning disabilities and people with physical impairments, people with sensory impairments, you know, multiple impairments … I think there are different aspect to a model – the social model. I think the barriers are different, I think this kind of attitudinal oppression, it takes on different forms. But you know, at the end of the day, if you can't use a bus because you're a wheelchair user, because you can't get on it so you can't use the bus, if you don't use the bus because the bus driver is so horrible to you because you've got a learning difficulty and takes you a bit longer to count out the money, or because you get bullied on the bus, then you're not going to use the bus. If you don't use the bus because the last time you were on it you weren't very well, and therefore, perhaps, I don't know, you shouted a lot, or something, your behaviour was 'strange' and you were asked to get off it, and the bus driver said never get on this bus again, you're not gonna use the bus. And for me the social model is about all of that, it's like, well what do you do? Well you change the attitudes of the people that drive the bus, the people that get on the bus and you put a damn ramp on it. But all of those things they are three very different reasons for you facing oppression, and barriers, but actually they all boil down to the same three things – which is people's negative attitude, inaccessibility, and people not wanting to include you, or understand you. So for me the social model is capable of all that, but I do recognise that it has been limited in the way that it's been developed.**

> **Well of course because it makes links between the struggle for the liberation of people with physical impairments and the struggle for the liberation of people with emotional**

impairment, right, or psychological impairment, or whatever language you want to use. I think that it's important to build the link between one movement for liberation and another. Also I think it's important to de-individualise people's forms of psychological distress … and see them linked to one another both in response to systemic forms of oppression like rape and incest, and also in terms of systemic responses to the oppression, so we're not just saying 'OK, I'm going to be a good mental health person and take my [prescribed drug] today' or whatever, 'no, I'm going to be a proud psychiatric survivor and I'm gonna challenge the notion that something is wrong with me and argue that something is wrong with the society that won't accept me'.

Participants also highlighted that such a social model needed to take account of personal (for example, psychological) as well as social issues:

I think it probably needs … if it's going to be holistic, it probably needs to be a collaborative model, and certainly take seriously … psychological factors being part of it, whatever that may mean. Because I often think that psychology is the poor relation actually, you know, it carries on doing little things in little ways that end up being quite important, like CBT [cognitive behavioural therapy]. I wouldn't certainly think that CBT is the answer for everything either, but I mean it does actually do some very useful things that actually psychological approaches tend to be quite invisible, they are not part of the debate a lot of the time.

Some problems with a social model of madness and distress based on the social model of disability were also identified. For example, it could result in a tendency to see all distress as the same and reinforce the negative labelling of mental health service users and reinforce an unhelpful perception of them as a separate and permanent group:

I think it would be quite dangerous really, because … there would be words that categorise it to the type of person and could be quite damaging to other mental health users and the social model of disability.

Well no I don't because [a mental health problem is] variable … it's variable in how much it affects the individual … So that's the problem with … disability because if you put [a mental health problem] under one heading and give it a label, it's going to be looked upon as fixed, and that's a pitfall.

Labelling, without a doubt, it would be terrible, stigma, it would be a terrible thing to do.

There was also a view that a social model of madness and distress might challenge some conventional thinking about the social model of disability. This point was developed when participants were asked if they thought mental health service users had an equivalent impairment to that underpinning the social model of disability. While most participants were familiar with the social model of disability and could see the disabling effects of being a mental health service user, many were reluctant to see themselves as having an impairment:

To me, as I say it would have to fit [the social model of disability] and maybe challenge thinking around [the] social model of disability, but the people I know are very open minded about it, I think there are people who maybe because of their own prejudices can't get their head round it, so maybe it would be one day we would sit down and think of this

social model of madness and distress and it would look like something that people could relate to, but it would also look similar to the social model of disability I would say.

I've never, you know, I reflect what the disabled people movement suggests and try to deflect stupid criticisms, you know, it took sort of people with whatever health problem they got, or see themselves, or have been seen as … you know, because if you grow up with a visual impairment you don't realise you're impaired until you actually come across somebody's who's not, if you see what I mean, or society. You know if you behave in a certain way, if that's the normal way of behaving or if you've never been told it's normal, then you don't know you're different if you see what I mean. We all identify with each other, but we don't live in a society, despite the facts that we speak about individuality, we really don't like difference, do we? Anybody who's slightly different, reacts differently, get 'em out as quickly as possible, or try and change them. I mean the other thing that I always say to students is how long it's going to be before normal breasts are not normal? Because of plastic surgery, if you see what I mean, and that's the point, that really is the point.

But you've got to believe you've got an impairment if you have [the social model of disability] … But some people never have any problems, they never take medication they're never hospitalised. But there are many, many people with mental ill health who are often hospitalised, who are on severe medication, who are having, you know, severe problems and if that person [feels] that these symptoms are real, it is believed that they have [an impairment], and that's about it.

This was an important barrier for a number of people in the way of seeing the social model of disability as helpful or transferable to them as mental health service users. So while many felt they were 'disabled' as mental health service users, they did not necessarily see this as underpinned by some actual specific impairment. Thus, while they might value being part of a wider movement and sharing a common philosophy, the issue of impairment represented an important obstacle for them:

I don't know, I think it's very complex, but because I think that mental health service users should be part of the social model, should be part of the disability movement, part of the service user movement …which is why there is a disability movement then. The word impairment, I'm not that happy with the word impairment, because, you know, it's about limits isn't it?

I'm not sure that it's a fixed … and permanent the way some impairments are fixed, like visual impairment, or hearing impairment, because somebody with a mental health [problem] can fluctuate, whereas somebody with a sensory impairment …

This issue was highlighted in exchanges in two of the group discussions. In the first, it went as follows:

I think that's on the same level as we said about disabled, you gotta … you don't want to admit to it, but if you really think long and hard it is.

Impairment.

Psychological impairment.

Impairment, it's slightly different isn't it, impairment?

Whether it is the medication, or whatever, you are impaired because the medication slows you down, and you can't be the person that you used to be.

If you feeling really good one week you can achieve so much, then the next week if you're down that's an impairment.

If it's impairment, you couldn't … like X was saying that it slows you down, that's from the medication it's from the actual illness, it's the illness that's impairing you it's the medication that's impairing you.

But without the illness you wouldn't need the medication.

But as X was saying his [impairment] … his mental illness was disabling him.
I think it is the illness that disables you because at the end of the day they have all these symptoms.

If I said to you what do you class as impairment I would say people with bad eyesight, people who … and if you really put it down it's like a disability again, so is disability and impairment seen the same?

No.

Exactly.

There are different types[of impairment] are there? So ours is psychological?

Yeah that's right.

You've got the physical and then you've got the psychological.

Yeah but it is, this is a psychological thing yeah.

The second exchange went as follows:

Using the social model approach, I talk about impairment being the thing that's different about your body or your mind, the fact that it doesn't work in the same way as everybody else's or the perceived majority. And so from that perspective, I suppose I would say that people do have an impairment in the same … in a similar way because something isn't quite working in what is perceived as normal. So I suppose if you take … you know your legs don't work, then you're not perceived as normal. If you get very ill, and you behave in way that is seen as being out of the ordinary … then I guess that is an impairment as far as I'm concerned. But I am reluctant about saying that I have any right about giving anybody else an identity! I don't think I do, but …

I think the answer to that is yes, but I don't think that everybody would think that, I know that there are a lot of people who wouldn't want to see themselves as disabled, I mean I know there are people on both sides of the camp who don't wish to join up. I think broadly speaking I think the answer is yes, when it comes to people with – I think I tend to make a … this is not very right on, OK, what I'm about to say, I think I make a distinction between

people who've got serious long-term problems and people with, you know, less serious, perhaps more transient problems, I think I tend to make a distinction at this point and say that actually, yes, some people do have an impairment in those terms, and some people don't maybe. I don't know if that's the correct answer but at least this is confidential so you won't think less of me!!

Um … but the impairment is only temporary.

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

Yes absolutely, absolutely. I think that's absolutely the way to think about it.

Yes, definitely.

It could be argued that some of the comments made by participants were the result of an inadequate understanding of the social model of disability. Certainly we had referred to 'impairment' in terms of 'perceived impairment' in this project. However, in the original form of the social model of disability, impairment tended to be seen as something objective, a measurable absence of or lack of functioning in some bodily part or mechanism. What some comments from participants suggest is that if the model is to be transferrable to mental health issues, then impairment may also need to be seen, at least in some cases, as socially constructed, like disability.

The views, concerns and uncertainties that participants felt and expressed to us reflect a disquiet with the idea of 'impairment'. This led at least one participant to feel that if a social model of madness and distress were to be developed, it might need to be distinct from a traditional social model of disability thinking, unless that were open to change:

Now I've said could be, but I'm not sure why we would want [such a social model]. My concern … I think my concern is that you end up with separation and I don't think that helpful. But, if the current social model [of the disabled people's movement] isn't going to change, then I think you do need your own model so that people can take on board what are their issues and what aren't their issues.

5 Conclusion

This was a small-scale project and its limitations have to be acknowledged. For example, it included few young people with experience of using mental health services. It does, however, point to some further areas of work that we hope will be undertaken. Also, it does seem to highlight some very strong concerns among mental health service users and disabled people about the current conceptualisation of mental health issues, as well as pointing to a present lack of consensus over developing alternative ways of thinking, building on a social model of disability. A number of clear findings emerge:

- There is significant agreement that the existing dominant medicalised individual model of mental illness is negative in effect;

- This medical model is seen as very powerful among professionals, in society generally and also among service users, shaping understanding and attitudes;

- The medical model is seen as having a powerful part to play in perpetuating the stigma associated with madness and distress;

- Service users' views about the social model of disability (with which most were familiar) are complex and varied;

- At the same time there is strong support for more social approaches to understanding and responding to 'mental health issues'. People feel that broader issues need to be taken more into account to counter the individualisation of mental health issues;

- Most participants feel that they experience barriers as mental health service users, just as disabled people have highlighted the barriers restricting them;

- There is no consensus about terminology in this field among service users. This relates to the negative associations of most of the terminology in use and in turn creates significant barriers and problems in the way of advancing thinking and action towards different understandings of mental health issues;

- Some service users can see real gains in developing new ways of thinking about mental health issues, building on a social model of disability. They see this as encouraging greater unity and shared understanding among different groups of service users and a conceptual framework more suited to valued approaches to personal and social support;

- However, some service users also offer challenges to some existing understandings of a social model of disability and some other service users see the framework of a social model of disability as less helpful;

- A particular issue which creates concerns for people is the concept of 'impairment' as part of the social model of disability. Some mental health service users feel that they and other mental health service users may not have an impairment and that it may be unhelpful to apply this idea to them;

- The issue of impairment prompted some service users to consider that more thought was needed about the social model of disability, a possible social model of madness and distress and the relation there might be between the two.

One of our readers commented:

> … [perhaps] there is no such thing as the social model of madness and distress, as there is no shared experience or concept of madness and distress. We may be talking about many different experiences, illnesses, traumas etc., arbitrarily grouped together by psychiatric classification systems … However, clearly there is much to gain from a common approach to social and legal rights, greater equality and equity and better systems of support.

As this reader also reminded us, mental health service users, like many disabled people, are concerned that any understanding of their situation takes full account of the personal issues they face and the support needs they might have as well as broader social issues and interactions.

This project has raised many subtle and complex issues in relation to understandings of 'mental health', madness and distress. Their importance and the difficulties they may create for mental health service users/survivors seeking to secure their rights and needs should not be underestimated. But we should also remember that disabled people have already had to grapple with many similar difficulties and that there may be lessons to learn from this.

While the people who took part in our project largely saw the medical model of mental health as damaging and destructive, it is still the model that most service users have internalised and are most familiar with. But the same also continues to be true for many disabled people, who are still not aware of the social model of disability and its liberatory potential; and yet the disabled people's movement and disability equality continue to make progress. So the barriers are not insuperable – a point that should encourage us as survivors. Also, there is still much work to be done in developing the social model of disability in relation to disabled people, so if there are problems in relation to it, these do not solely relate to its application to mental health service users/survivors. This was highlighted by comments from another of our readers who wrote:

> I would like to point out that there are many disabled people who find that the conventional social model does not easily fit their situation. Sometimes, for example, it is about the experience of impairment, not just about social barriers. There are those of us who have conditions such as epilepsy … These are intermittent and unpredictable in their effects, strongly demonised, very isolating (which leads to a high suicide rate). Medication and its side effects are very significant, and it is possible to achieve control over the effects of the impairment, leading to the question, 'Have I stopped being disabled?' (To which I would suggest that the answer is: 'No. You'll always live with the possibility hanging over your head, and always have to deal with other people's attitudes'.) The questions of whether or not to come out, who to and when are massively important. These are not the same issues faced by wheelchair users, but most or all of them are shared with some mental health system service users. I suggest that it would be useful to build links between service users and those disabled people for whom the conventional social model does not provide a full analysis of their situation.

6 Recommendations

This study highlights a significant gap between many mental health service users and current thinking among disabled people about their lives and policies. As we have seen, while disabled people frequently find the social model of disability helpful and identify with it, mental health service users seem much less likely to feel it can be helpful for them and are also often reluctant to identify as disabled. Yet government policy is increasingly building on the social model of disability and the philosophy of independent living developed by the disabled people's movement. This is reflected both in the Prime Minister's Strategy Unit Report of 2005, *Improving the Life Chances of Disabled People*, and the government's *Independent Living* strategy published in 2008 (Prime Minister's Strategy Unit, 2005; Office for Disability Issues, 2008). For many disabled people, these developments represent a very positive development, offering opportunities and hope for greater equality and the removal of barriers in the future.

Yet while mental health service users are largely included as disabled people in such policies, many do not identify with them and instead are becoming part of a new policy model, the 'recovery' model. This is still essentially based on an individual medicalised model of mental illness, although some mental health service users/survivors see it as helpful and feel that it helps emphasise service users' strengths and supports a more person-centred approach to services and support. The likelihood is that mental health service users may be disadvantaged by becoming isolated from other disabled people and the more rights-based policies that are emerging in relation to them. It is likely to be helpful for mental health service users and their organisations to have more opportunities to familiarise themselves with the social model of disability and to discuss its possible relevance to them.

Government policy developments, like the *Independent Living* strategy, have important potential as a way of connecting mental health policy and mental health service users with broader disability policy, developments, theory and discussion. Moves to mainstream direct payments and individual budgets across service user groups may have the same helpful effect. At the same time there clearly needs to be more debate which connects disability and mental health issues and discussions, if such developments are to be fully effective. They also point to the importance of mental health service users addressing social approaches to their circumstances, rights and needs more carefully, subjecting both the terminology and theory of social model thinking to more critical consideration.

As we noted earlier, the social model of disability is a concept undergoing continual development and discussion (Thomas, 2007). A gap seems to have opened up between grassroots understandings of the social model of disability and the complex and sophisticated discussions taking place in academic and research settings. Ordinary disabled people often talk of the social model of disability as being 'like a light bulb' that helped them to understand the barriers and oppression they faced and to think differently and more positively about themselves. For them the social model was not something obscure or difficult that they had to try and make sense of themselves, but rather something that was enlightening.

In the light of this, the present initial exploration of a possible social model of madness and distress points to some potentially helpful next steps. These include:

- sharing the findings of this project more widely among mental health service users/survivors, disabled people and the wider disabled people's movement;

- facilitating further opportunities for mental health service users and their organisations to discuss these findings and explore their implications;

- sharing the findings from this project with the Social Perspectives Network as a basis for follow-up action;

- identifying priorities for action, particularly in relation to the negative effects associated with current dominating medical models of mental health issues and the negative media presentation of mental health matters;

- setting up an ongoing group, or linking with a suitable existing group, of mental health service users to take forward discussion on the social model of disability in relation to mental health service users and the further development of a possible social model of madness and distress;

- for existing proponents of the social model of disability to explore how it might be more accessible, particularly for mental health service users, so that they are able to gain a better understanding of it in relation to themselves;

- for survivor leaders and activists, particularly those concerned with the movement's value base and philosophy, to explore the social model of disability in more depth, considering if and how it might be developed better to address and include mental health issues;

- providing opportunities for mental health service users to become more aware of disability issues generally and the social model of disability specifically, and how these might be relevant to them;

- supporting mental health service users/survivors and their organisations to learn more about the work of the disabled people's movement and legislation/rights issues that they can benefit from. This will help them to secure rights and work together with disabled people's groups on common issues, such as direct payments, individual budgets, personalisation and self-directed support;

- undertaking a parallel examination to that reported here of service users' views, exploring mental health workers' views of social approaches to mental health, any differences there may be between them and particularly the relevance of the social model of disability;

- providing increased opportunities for mental health workers, particularly psychiatrists in qualifying and other training, to become more familiar with social approaches to mental health issues and specifically the social model of disability;

- creating more opportunities for different groups of service users to come together and explore ideas like the social model and Independent Living together, thinking through possible similarities and differences. Shaping our Lives, the national user-controlled organisation and network, works across different user groups and finds this a helpful way of breaking down barriers and sharing understandings and experience;

- challenging negative labelling and stigma. Labelling and stigma emerge again in this project as a major barrier for mental health service users. Some, however, have begun to challenge negative labels and identities imposed on them. It will be helpful to explore how mental health service users might be able to challenge the negatives attached to them and take greater pride in who they are, possibly reclaiming language that has been attached to them for negative and hostile reasons;

- challenging internalised stigma and oppression. The stigma and oppression experienced by mental health service users/survivors can become internalised, having an additionally damaging effect on their self-esteem and sense of self and possibly perpetuating their distress. More attention needs to be paid to ways in which this can be overcome, particularly through the collective and peer support that can be offered by survivors' own organisations and movement.

Reading material

Beresford, P. (1999) 'Making participation possible: movements of disabled people and psychiatric system survivors', in T. Jordan and A. Lent (eds), *Storming the Millennium: the New Politics of Change*. London: Lawrence and Wishart, pp. 34–50.

Beresford, P. (2000) 'What have madness and psychiatric system survivors got to do with disability and disability studies?', *Disability and Society*, Vol. 15, No. 1, January, pp. 168–72.

Beresford, P. (2002) 'Thinking about "mental health": towards a social model', *Journal of Mental Health*, Editorial, Vol. 11, No. 6, December, pp. 581–84.

Beresford, (2004) 'Madness, distress, research and a social model', in C. Barnes and G. Mercer (eds), *Implementing the Social Model of Disability: Theory and Research*. Leeds: Disability Press, pp. 208–22.

Beresford, P. (2005a) 'Developing the theoretical base for service user/survivor-led research and equal involvement in research', *Epidemiologia e Psychiatria Sociale* (EPS), Vol. 14, No. 1, January, pp. 4–9.

Beresford, P. (2005b) 'Social approaches to madness and distress: user perspectives and user knowledges', in J. Tew (editor), *Social Perspectives in Mental Health: Developing Social Models to Understand and Work with Mental Distress*. London: Jessica Kingsley, pp. 32–52.

Beresford, P. (2005c) 'Developing self-defined social approaches to distress', in S. Ramon and J.E. Williams (eds), *Mental Health at the Crossroads: The Promise of the Psychosocial Approach*. Guildford: Ashgate, pp. 109–23.

Beresford, P. and Campbell, P. (2004) 'Participation and protest: mental health service users/survivors', in M.J. Todd and G. Taylor (eds), *Democracy and Participation: Popular Protest and New Social Movements*. London: Merlin Press, pp. 326–42.

Beresford, P. and Wilson, A. (2002a) 'Madness, distress and postmodernity: putting the record straight', in M. Corker and T. Shakespeare (eds), *Disability/Postmodernity: Embodying Disability Theory*. London and New York: Continuum, pp. 143–58.

Beresford, P. and Wilson, A. (2002b) 'Genes spell danger: mental health service users/survivors, bioethics and control', *Disability & Society*, Vol. 17, No. 5, pp. 541–53.

Beresford, P., Harrison, C. and Wilson, A. (2002) 'Mental health, service users and disability: implications for future strategies', *Policy & Politics*, Vol. 30, No. 3, pp. 387–96.

Campbell, J. and Oliver, M. (1996) *Disability Politics: Understanding our Past, Changing our Future*. Basingstoke: Macmillan.

Campbell, P. (1996) 'The history of the user movement in the United Kingdom', in T. Heller, J. Reynolds, R. Gomm, R. Muston and S. Pattison (eds), *Mental Health Matters*. Basingstoke: Macmillan, pp. 218–25.

Morris, J. (1993) *Independent Lives: Community Care and Disabled People*. Basingstoke: Macmillan.

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

Office for Disability Issues (2008) *Independent Living: a Cross-government Strategy about Independent Living for Disabled People*. London: The Stationery Office.

Oliver, M. (1990) *The Politics of Disablement*. Basingstoke: Macmillan.

Oliver, M. (1996) *Understanding Disability: from Theory to Practice*. Basingstoke: Macmillan.

Oliver, M. and Barnes, C. (1998) *Disabled People and Social Policy: from Exclusion to Inclusion*. London: Longman.

Prime Minister's Strategy Unit, Cabinet Office (2005) *Improving the Life Chances of Disabled People*. London: The Stationery Office.

Ramon, S. and Williams, J. E. (eds) (2005) *Mental Health at the Crossroads: the Promise of the Psychosocial Approach*. Guildford: Ashgate.

Sweeney, A., Beresford, P., Faulkner, A., Nettle, M. and Rose, D. (eds) (2009) *This Is Survivor Research*. Ross-on-Wye: PCSS Books.

Tew, J. (ed) (2005) *Social Perspectives in Mental Health: Developing Social Models to Understand and Work with Mental Distress*. London: Jessica Kingsley.

Tew, J., Gould, N., Abankwa, D., Barnes, H., Beresford, P., Carr, S., Copperman, J., Ramon, S., Rose, D., Sweeney, A. and Woodward, L. (2006) *Values and Methodologies for Social Research in Mental Health, National Institute for Mental Health in England and Social Perspectives Network, in association with the Social Care Institute for Excellence*. Bristol: Policy Press.

Thomas, C. (2007) *Sociologies of Disability and Illness: Contested ideas in Disability Studies and Medical Sociology*. Basingstoke: Palgrave Macmillan.

Wallcraft, J., Schrank, B. and Amering, M. (eds) (2009) *Handbook of Service User Involvement in Mental Health Research*, World Psychiatric Association. Chichester: Wiley-Blackwell.

Appendix I

How we carried out the study

The research project was carried out drawing on a user-controlled approach to research. This meant that the research was controlled by service users and it originated in a wider interest among mental health service users/survivors in alternatives to medicalised understandings of mental health issues. It also sought to equalise research relationships in its process and to support the personal empowerment of mental health service users/survivors and promote wider change in line with their rights and interests.

The focus of the project was to explore mental health service users' views about the conceptualisation of what tend to be called 'mental health' issues. This was to be achieved through exploring their own views about existing models of mental health, as well as views of wider understandings of 'mental health', and through examining how they conceive of experiences like their own, their views of the social model of disability and what applicability it might have to a 'social model of madness and distress'.

We used the term 'mental health issues' in talking with people about this subject, to avoid leading them through our own use of language. This is not our preferred term, but we have used it as it is commonly used and conveys a general meaning, without particularly leading people in their own thinking. There is no consensus about language in this field. All terms are likely to be offensive to someone and none necessarily has a shared meaning. We adopted the term 'mental health issues' as one that would be readily understood by a wide range of participants and which would create as few obstacles to understanding and participation as possible.

We deliberately involved a wide range of mental health service users in the project, including some who have themselves developed discussion about this subject, as well as others for whom it would not be something they had necessarily given thought to before. We also wanted to include mental health service users who had direct experience of physical, sensory and intellectual impairments, because of the insights this might offer them, and some disabled people who could contribute from their understanding of the social model of disability.

The research sample

The national study on which this report is based was carried out through a series of group discussions and individual interviews which included a total of 51 participants. We sought to offer participants a choice in how they took part in the project. Seventeen individual interviews were carried out, of which eleven were conducted by telephone interview, four face to face and two by email. Of those taking part in the individual interviews, five participants were male and twelve were female.

Four focus groups were also conducted, which included 34 participants. These were carried out in Bradford, Birmingham, Hereford and Sandwell. The focus groups included 15 male and 19 female participants. They offered participants opportunities for interactive discussions, to debate issues and to share and explore their own views and understandings. Thus, as can be seen from the tables below, of a total of 51 participants, at least 39 (see below) were people who identified as having direct personal experience of mental health issues/problems. All the participants were long-term users of health and social care services as mental health service users, disabled people, people with learning difficulties or some combination of these identities. Participants came from both urban and rural areas.

The method we adopted for selecting and recruiting participants was the snowball method, where one contact is used to lead to another, and then another. This resulted in the sample including a very diverse range of mental health service users and disabled people, although we are aware that the number of young

people was limited. None of the focus groups was held with members of a particular user group, although in many cases individuals did belong to a user group. Overall, participants included people involved in service user groups as well as those who were not, with a broad range of views and experience. While we cannot suggest that all viewpoints were included, we do know that the views of participants did not narrowly reflect any preconceptions that might have been held by the authors of this report.

The interviews and discussions

The group discussions and individual interviews were carried out using a semi-structured schedule, which consisted predominantly of open-ended questions in order to allow participants to answer in their own terms and to better reflect the experiences of mental health service users and disabled people. The schedule (see Appendix II) was piloted through an initial individual interview and seemed to work well as both a basis for individual and group feedback. Throughout both interviews and group discussions, the facilitator (Mary Nettle) tried to give minimal input so as not to influence the participants' responses.

Analysis

All interviews and discussions were transcribed in full. The framework for analysis was provided by the research focus and objectives with a commitment to reflect the experiences and ideas of participants. The interview schedule was followed as closely as possible in organising this report. Information from transcripts was organised into themes relating to the different sections of the schedule.

As the project sought to model a user-controlled research approach, it was important to reflect the concerns and ideas of participants as much as possible. A number of steps were taken in order to ensure this. First, the interview schedules were analysed qualitatively in order to reflect what participants said, rather than to quantify it numerically. For this purpose interview transcripts were analysed using a qualitative software program, NVivo 7. NVivo is a software program specially designed to aid qualitative analysis, providing a methodical tool for organising and storing data. Through NVivo the interview transcripts were coded and then organised into specific themes relating to each section of the interview transcript. Using NVivo ensured that quotes from the transcripts could be stored according to these specific themes.

Second, the transcripts were analysed manually to ensure that context had not been missed resulting in misrepresentation of what people said. The analysis was undertaken in the same manner as using NVivo, but the coding on the transcripts was conducted directly. The themes that emerged were then compared to those found using NVivo. There was a high level of consistency.

Third, to ensure that the report directly reflected what people had to say, their comments have been quoted in detail in order to demonstrate specific points of interest that arose from the interviews. Giving priority to such quotations also ensured as much as possible that the report did not speak for participants or reinterpret what they had to say.

Personal characteristics of participants

We were anxious to have as wide a range of participants as possible in this project. At the same time, we wanted participants to have the opportunity to give as much or as little information about themselves as they wished. As a result, information is available about the user group with which participants identified in all but five cases and information about their gender in all but six cases (see tables below). We only have information relating to age and ethnicity from the focus groups as they were asked to complete a personal details form, although we do know that participants who took part in individual interviews included people from a range of age groups.

Not all the self-completion forms were fully completed, which accounts for some gaps in information. While in the individual interviews participants were specifically asked how they personally

identified in terms of the user group they associated themselves with, other personal information was not required. Information about gender was provided where the interviewer was able to record it. As a result not all information about gender could be matched with what user group participants identified with for either focus groups or individual interviews.

Participants were not asked to disclose their sexuality and there were no specific mentions or references to sexuality. While it is therefore difficult to suggest that people's sexuality may impact upon their views or experience regarding the conceptualisation of mental health issues, the interviewer/facilitator felt that it was likely to play a part. Given that historically and in some societies homosexuality has been identified as a form of disorder for treatment, this is perhaps not surprising.

Table 1: Category of service user

Category of service user	Number (total 51)
Mental health services user/survivor	21
Disabled person (with physical/sensory impairments)	5
Person with learning difficulties	2
Mental health service user/survivor and disabled person	15
Mental health service user/survivor and person with learning difficulties	2
Mental health service user, person with learning difficulties and disabled person	1
Not known	5

Table 2: Gender

	Female	Male	Gender unknown
Mental health services user/survivor	16	4	1
Disabled person (with physical/ sensory impairments)	3	1	1
Person with learning difficulties	1	1	
Mental health service user/ survivor and disabled person	6	6	3
Mental health service user/survivor and person with learning difficulties	2	0	
Mental health service user, person with learning difficulties and disabled person			1
Not known	5		

Table 3: Personal identification by ethnicity (for discussion groups only, n = 34)

	White/White British	Mixed ethnicity	Black/Black British	Asian/Asian British
Mental health service user/ survivor	12		3	2
Disabled person (with physical/ sensory impairments)	2			
Person with learning difficulties	1			
Mental health service user/ survivor and disabled person	6		1	1
Mental health service user/survivor and person with learning difficulties			1	
Mental health service user, person with learning difficulties and a disabled person		1	1	
Ethnicity unknown	19			

Table 4: Participants' identification by age group (members of group discussions only, n = 34)

Age group	Total
0–20	0
21–30	2
31–40	4
41–50	13
51–60	10
61–70	3
71–80	0
Not known	2

Appendix II

Schedule for interviews and group discussions

Our understandings of mental health issues

Introduction

Hello.

Can I introduce myself? My name is Mary Nettle. Thank you very much for your help with this research project. I'd like to begin by telling you a bit more about it. The focus of this project is to find out more about how people, particularly mental health service users, understand and explain what tend to be called mental health issues. We want to find out more about how they think about mental health in order to help their views have more impact on policy and practice. Two of us are carrying out this project: Peter Beresford (who is directing it, based at the Centre for Citizen Participation at Brunel University) and Mary Nettle, a self-employed user consultant. This is a small-scale twelve-month project. We hope that it may lead to further work. We will work hard to tell people about what we find out from what you and others say in order to try and change things for the better. We are both users/survivors of mental health services and both involved in service user/survivor organisations. The project is being funded and supported by the Joseph Rowntree Foundation, an independent charitable funding organisation.

As I said, we are carrying out the project to learn more about what people think about the way that what are called mental health issues are and might be understood in our society, from their points of view. We are talking to three groups of people. First, mental health service users/survivors themselves. Second, people who are disabled, that is to say people with physical and sensory impairments. We are talking to them because of the ideas they may have had about disability. Third, we are talking to people who identify as both mental health service users and disabled people and who have both experiences in their lives.

The aim is to explore how people in these three groups understand issues from their perspectives and particularly to make it possible for people with experience as mental health service users to think about and explore what they understand by ideas of mental health, mental distress and madness. There is no agreed language in this field, so we hope that people won't find the language we use offensive or unhelpful and we apologise in advance if they do in any way.

We are carrying out this project mainly by organising a small series of discussion groups with people we know have an interest in these issues to learn from their ideas, expertise and experience. Unless people indicate otherwise for themselves as individuals, we will ensure that issues of confidentiality and anonymity are fully safeguarded so that people can be sure that they and their views will not be identified through taking part in this project. We will meet people's travel and support costs (please provide tickets and receipts) and will also be making a small payment to participants in recognition of their contribution.

We may also undertake some individual interviews for people for whom that is more convenient and accessible, and also we may undertake a small-scale survey, both through email and also by telephone interview. We want to make it possible for as wide a range of people in the three groups we have identified to take part as possible.

We plan to produce a report of this project. We will keep people in touch with our findings and provide a copy of the report in suitable accessible format for them. We will return to this at the end of the discussion.

Is everything clear to everybody?

Would you like to ask me any questions?

I should like to tape record this discussion so that we have an accurate record of what you say. Is that OK?
We will keep the tapes and other information about the project in a safe and secure place and after a fixed period we will destroy the tapes.
I shall now begin if that is OK with everyone.

Schedule questions

I want to begin by asking you some questions about how people think about mental health issues.

1. How do you think that mental health issues, mental health problems are mainly understood in our society?

2. What kind of a model of mental health issues/problems do you think underpins:

   a. Professional thinking and mental health policy?

   b. Public understanding?

3. Do you think that such a model/such an approach to understanding is helpful?
   Yes/No/Don't know
   Detail

4. What benefits do you think such a model/approach to understanding can offer?

5. Do you think it can create any problems?
   Yes/No/Don't know
   Detail

Next I'd like to ask you how you think about mental health issues.

6. Can you tell me how you personally understand mental health issues? What kind of a model, framework or set of ideas, if any, do you have? Here we would like to hear your views, not what you think may be wider views among professionals or in society generally.

7a. Do you see your way of understanding mental health issues as a social or holistic approach to thinking about and defining them? By social and holistic we mean an approach which takes account of all the issues that may relate to mental health matters, not just what is thought to happen within the individual person.
   Yes/No/Don't know
   Detail

7b. We are using both the terms social and holistic. Could you tell us if you prefer one of these terms – social or holistic – in this context and could you tell us why?

8. Do you think that such a social or holistic way of thinking about and understanding what is included as mental health issues is helpful?
   Yes/No/Don't know
   Detail

9. What benefits do you think such a social or holistic approach to thinking about mental health issues may offer?

10. Do you think that such a social or holistic approach to understanding mental health issues can create any problems?
    Yes/No/Don't know
    Detail

11. What do you think that a social or holistic model of mental health would need to include/take account of to be as helpful as possible?

    I'd now like to ask you some questions about the social model of disability.

12a. Are you familiar with a social model of disability?
     Yes/No/Don't know
     Detail

12b. If YES, could you tell me what it means to you?

12c. If NO, offer a brief explanation. (This is how the social model of disability is generally defined: the social model of disability draws a distinction between the individual impairment of the person, for example lacking a limb or a sense or a limb not working, and disability, which it takes to mean the oppressive social reaction or response that there is in society to people with impairments, which creates barriers, oppression and discrimination and restricts people's rights.)

13. Do you think that the social model of disability can relate helpfully to the experience of mental health service users/survivors and might be helpful for an understanding of mental health issues?
    Yes/No/Don't know
    Detail

14. Do you think that the social model of disability has any limitations in relation to the experience of mental health service users/survivors and mental health issues?
    Yes/No/Don't know
    Detail

    I'd like now if it is OK with you to ask you how you identify personally. (If you like I could instead leave this for you to complete separately at the end of the interview.)

15a. For the purpose of this project, can I ask you if you identify as:

     A mental health service user/survivor
     A disabled person (someone with physical/sensory impairments)
     A person with learning difficulties
     A mental health service user/survivor and disabled person

A mental health service user/survivor and person with learning difficulties
Other: please describe.

15b. For mental health service users ONLY:
Could I ask you if you see yourself as a disabled person (by reason of your experience as a mental health service user)?
Yes/No/Don't know
Detail

15c. Could you please tell me why?

I would now like to ask you some questions about the status of mental health service users/survivors

16. Do you think that mental health service users experience:
i) Oppression?
Yes/No/Don't know
Detail

ii) Legal and other restriction of their rights (including and as well as compulsory restrictions under Mental Health Act Sections)?
Yes/No/Don't know
Detail

iii) Barriers?
Yes/No/Don't know
Detail

Now I would like to ask you some questions about the terms 'madness' and 'distress'.

17. Some mental health service users/survivors use the terms 'madness' and 'distress' instead of 'mental health' and 'mental illness'.

What do these terms mean to you?

18. How do you think madness and distress are understood in:
i) the mental health system?
ii) our society more generally?

19. What do you feel about a model of madness, distress or mental health based on the idea of 'mental illness'?

20. We have talked about the social model of disability. Do you think that there is an equivalent social model of madness and distress?
Yes/No/Don't know
Detail

21a. Do you think such a social model of madness and distress could be helpful?
Yes/No/Don't know

If YES
21b. What do you think it would look like?
Detail

If NO
21c. Why do you think this?

If YES
21d. How do you think it would relate to a social model of disability?

22. What implications do you think a social model of madness and distress would have for the social model of disability?

23. Do you think that mental health service users/survivors have the equivalent of an impairment as discussed in the social model of disability?
Yes/No/Don't know
Detail

24. Finally, are there any questions you would like to ask us?
Yes/No/Don't know
Detail

25. Would you like any additional information about this project?
Yes/No/Don't know
Detail

Conclusion
Finally, could I say thank you now for taking part in this project. Your contribution will be very helpful. We are anxious to keep people in touch with the outcomes from this project, so I will ask you for contact details. Again these will be treated in strictest confidence and anonymity. Thanks very much again.

Participants' contact details

(This may be one contact point or information for individuals.)
Please obtain relevant contact name, address, phone number and email address.
If possible obtain contact details for all participants.

Check and log
Would they like a copy of the project report?
What format would they like it in (at this stage we can offer hard copy, large print, electronic format)?
Check if there are any additional requirements; for example, simple English, other languages, and please record.

Acknowledgements

About the authors

Peter Beresford is a long-term user of mental health services. He is Professor of Social Policy at Brunel University and Chair of Shaping Our Lives, the service user organisation and network. He is a writer, researcher, educator and campaigner with a long-standing involvement in issues of participation and empowerment.

Mary Nettle became a user of mental health services in 1978 and turned this negative into a positive in 1992 by becoming a mental health user consultant. She is involved in presenting the user perspective in all aspects of mental health, with a particular interest in user led research. She is also Honorary Fellow of Brunel University in the Centre for Citizen Participation; Honorary member of the National Institute for Health Research Faculty and member of Health Technology Assessment psychological and community therapies panel; Member of INVOLVE, ensuring the service user voice is included in a meaningful way by those undertaking health, social care and public health research; Working as a Mental Health Commissioner for the Care Quality Commission to ensure that the rights of patients detained under the 1983 Mental Health Act are upheld; Chair of the European Network of (ex-) Users and Survivors of Psychiatry (voluntary).

Rebecca Perring has a background in the social sciences with a particular interest in gender and equality issues. She has worked as a researcher in the social sciences, contributing to projects in the areas of education and health. She currently works in the field of social housing with homeless individuals and young families.

**Available in
other formats**

Investors in Diversity
www.iiduk.com

recycle
When you have finished
with this please recycle it

**JOSEPH ROWNTREE
FOUNDATION**

www.jrf.org.uk