Towards a Social Model of Madness and Distress? Exploring what service users say

Findings Informing change

November 2010

This national study explores with mental health service users what models they feel underpin current thinking in mental health policy and practice, what effects this may have and what kind of model they think might be helpful for the future.

Key points

- Most service users believe that a medical model based on deficit and pathology still dominates public and professional understanding of mental health issues, shaping attitudes and policy.
- They largely see such a medical model as damaging and unhelpful.
- The labelling and stigma following from a medical model of mental illness emerge as major barriers for mental health service users.
- Service users see social approaches to mental health issues as much more helpful. They feel that broader issues need to be taken more into account to counter the individualisation of mental health issues.
- They have mixed and complex views about the social model of disability and how helpful a related social model of madness and distress would be.
- The study highlights the importance of developing discussion, particularly among mental health service users and their organisations, about social approaches to mental health issues, policy and practice, building on the social model of disability as a basis for improving the life chances of mental health service users.

The research By Peter Beresford, Mary Nettle and Rebecca Perring



Introduction

There is currently a growing interest in 'recovery' in mental health policy and practice and a desire to challenge the negative stereotyping and stigmatising of mental health service users. The social model of disability has highlighted the key role of social barriers in restricting the lives of disabled people and its value in challenging and overcoming these barriers is now increasingly recognised in public policy.

There has been more emphasis on social approaches to mental health in recent years, reflected, for example, in the establishment of the Social Perspectives Network. There have been some initial discussions about a social model relating to mental health among mental health service users/survivors. However, as yet, this has not been widely explored or developed. Helpful ideas developed by disabled people like the social model of disability and independent living have begun to have a positive influence on public policy and practice. However they have had little impact on mental health policy or mental health service users. Instead the idea of 'recovery' has become increasingly influential in this field, although it has also come in for criticism because of its essentially medicalised origins.

The aim of this project was to try to open up and take this discussion forward. Seeking the views of service users, it focused on four main issues:

- 1. How mental health issues are understood in society;
- 2. What personal understandings service users have of mental health issues;
- 3. What their views about the social model of disability are in relation to mental health; and
- 4. Their views about a social model of madness and distress, building on a social model of disability.

1. How are mental health issues understood in society?

The general consensus of participants in the project was that mental health issues are poorly understood in society. Participants felt that mental health issues are associated with fear and danger. This 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 still to dominate in societies like the UK, to have few benefits to offer and to be largely negative in effect. Participants saw such a model still dominating professional, public and indeed most service users' understandings of mental health issues – mainly in an unhelpful way.

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 its 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.

I think they are mainly understood as something to be feared, to be kept a distance from, very much associated with violence, either towards ones self or other people, but particularly towards other people. Because the medical model implied deficiencies and deficits, it led to people being negatively stereotyped and stigmatised:

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'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.

2. What personal understandings do service users have of mental health issues?

Most participants felt that mental health problems were a complex issue, which affected people in different ways. They 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. They felt that there wasn't one way of understanding mental health issues because of the range of different problems and issues that could affect people in a variety of ways.

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

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. Yeah it isn't just something that happens within the individual, you can't place it all within the individual when you look. Service users felt that to be successful, a social approach to understanding mental health issues would need to take account of people's individual and different needs and their psychological state, as well as shared social circumstances, experiences and barriers. 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 usercontrolled support services. It also chimes well with government and broader political commitments to extend the use of personal budgets, to increase 'choice and control', both in social care and in the National Health Service. More would need to be done to provide better quality and a wider range of support services for people and to challenge existing barriers restricting people's access to support.

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

Most participants in this project were familiar with the social model of disability, understanding 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. But there was no agreement about whether it related helpfully to mental health issues. Instead service users were divided in their views. Some service users feared that the association of the social model with disability would add to the stigma they faced. There was also a feeling that disability and mental health issues were different and that the idea of 'impairment' underpinning the social model misrepresented the experience of mental health service users.

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.

5.Their views about a social model of madness and distress building on a social model of disability

There were also strong disagreements among service users when discussing the idea of a social model of madness and distress. This was because while they were generally unhappy with a medical model, they were also wary of non-medicalised terms like 'madness'. As a result this made discussion difficult and had helped to discourage it.

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

There was nonetheless 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 participants 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.

One of the benefits seen for such a model was that it would help create solidarity and shared understandings between different user groups, strengthening them and increasing their effectiveness, as well as increasing opportunities for collaboration and joint action. It would renew understanding about mental health issues and could help highlight the links between different people's distress and make clearer how individual distress might be associated with broader oppressions and discrimination. There was also some sense that that there needed to be recognition that the barriers that mental health service users face may sometimes be different, as well as similar, to those which people with physical, sensory and intellectual impairments face.

Conclusion

Building on the evidence from this project, key next steps were seen to be developing discussion about these issues among mental health service users/ survivors and with survivor leaders and disabled people and their organisations, to identify priorities for action, especially joint action and to explore the implications for the social model of disability of further developing a helpful social model of madness and distress. A series of recommendations are offered to this end.

About the project

This report is based on 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 draws primarily on the views of a wide range of mental health service users. A total of 51 people took part through both individual interviews and group discussions.

Further information

For more information, contact Peter Beresford at the Centre for Citizen Particiption, Brunel University, at peter.beresford@brunel.ac.uk or on 01895 268741.

The full report, **Towards a Social Model of Madness and Distress?** by Peter Beresford, Mary Nettle and Rebecca Perring is published by the Joseph Rowntree Foundation.

Published by the Joseph Rowntree Foundation, The Homestead, 40 Water End, York YO30 6WP. This project is part of the JRF's research and development programme. These findings, however, are those of the authors and not necessarily those of the Foundation. ISSN 0958-3084 Read more Findings at www.jrf.org.uk Other formats available. Tel: 01904 615905 email: info@jrf.org.uk





Please recycle this when you have finished with it.