FROM MENTAL ILLNESS TO A SOCIAL MODEL OF MADNESS AND DISTRESS

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With thanks

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There are growing concerns about UK mental health policy and services. They are widely seen as being in 'crisis', chronically underfunded and having fallen far behind physical healthcare. There are also more fundamental worries that they are over-reliant on a narrowly-based medicalised conceptual framework which can be stigmatizing and unhelpful for service users.

FOREWORD

When I wrote the foreword to the 2010 first stage report, I was very excited that a project was taking place regarding the social model of disability and its relevance or not, to mental health. It was also important that the research was asking the people that matter, those with mental health issues themselves. Those that don't know assume all sorts of things, often wrongly about those that do. And sadly, this can still be found among the most important people in society. The fact that the work was being carried out by people who identify as having mental health issues is critical to the questions being formulated and the understanding of the answers that come back.

I welcome now this new project five years on, but instead of being happily excited, it feels like an urgent necessity that this work continues. The report highlights that welfare reforms, which are experienced as massive cuts, are hitting people hard, yet the system still does not anywhere near understand the subtleties of people's mental health needs and what should be invested to enable them to be contributing members of society. Massive cuts to social care and mental health service provision means that only people with the most acute problems receive any attention, yet the stigma that arguably all people with mental health problems feel from a discriminatory society is just as acute.

So along with new views of a social model of madness and distress, we have views on social approaches to mental health issues. There is also some critique of the 'recovery' paradigm that mainstream services hold dear, yet many service users feel they don't actually own it and only some can even identify with. Indeed, as if more needed to be said, it is quite clear that the medical model does not do justice to our experiences. These concepts deserve more thorough exploration, and I have no doubt this will continue amongst us.

It is quite clear that in these times of 'austerity' there is a disjointed approach to dealing with people with mental health issues, and that far too many are feeling they are losing out on what should be there to help and also enable them to live fulfilling lives. I said last time, rather romantically looking back, that the report then should light a fire under the debate that needs to crackle and roar. This time I hope this work throws accelerant onto that fire as a shining beacon of critically important matters.

I take heart though in seeing that the disability movement mantra "nothing about us without us" is now being used more widely amongst mental health service users and survivors. It is quite clear to me that plenty remains to be said and done. Read this report to see what you can do about it!

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SUMMARY

In 2010, the Joseph Rowntree Foundation published the findings of a national project exploring the views of mental services users/survivors and disabled people about how they felt mental health issues were understood in society and how they themselves understood them, *Towards a Social Model of Madness and Distress?*. This highlighted that most participants felt that a medical model dominated both public and professional thinking and that this was stigmatising and unhelpful and that further discussions about more social approaches to mental health were needed.

The Foundation supported a second stage project to make possible such discussions; to gain the views of a wider range of mental health service users/survivors and, to find our more about how more social understandings of mental health might be taken forward. This report documents its findings. These include:

1. Most service users who took part feel that the public and professionals interpreted metal health issues through a medical model as a medical issue, seeing a problem primarily in the individual. While many service users have themselves also internalised such a medical model, they associate it with an over-emphasis on drug treatments and most see it as stigmatising and damaging.

2. While there are widespread concerns about the medical model and associated terminology among mental health service users surveyed, service users are divided about the use instead of terms like 'mad' and 'madness'. Some thought they should be reclaimed, but others that they have too many negative associations. While there is increasing interest in the term 'madness', with the emergence, for example, of 'mad studies', there does not yet seem to be widespread support for such language among service users themselves.

3. There was again a strong lack of agreement about the social model of disability. Some service users find it helpful as a basis for understanding their experience and situation. Others reject it and do not think it can be helpfully applied to mental health issues or wish to identify as disabled people. There are particular objections from some service users to the idea of having an impairment, although some also raise subtle and complex issues about their identity. At the same time many service users feel it is possible and helpful to identify with and link with the broader disabled people's movement, while retaining their own distinct identity as mental health service users. It seems clear from this project's findings that any attempt to impose the social model of disability crudely on mental health issues and mental health service users is unlikely to gain widespread support from service users at present.

4. Because the idea of 'recovery' has become a guiding principle for UK mental health policy and provision since the first stage project, we asked participating service users about it. Participants have very mixed views on whether 'recovery' is helpful for mental health service users/survivors. Most feel that the idea could be helpful, but that the policy as implemented is not. It perpetuates a medicalised individual model of mental health. It was not based on listening to service users. There are strong feelings that the idea, which was supposed to be user-led, has been hijacked by a narrowly framed government policy, which puts increasing responsibility on the individual service user to deal with their difficulties. Its central aims are seen as saving money, cutting services, and most important getting people off benefits and into paid work, regardless of how helpful or realistic it is for them.

5. While divided about the social model of disability, most service users who took part in the project feel that social approaches to mental health, which take account of the whole person and wider societal issues affecting them, are the most helpful. Some feel that such social approaches need to be incorporated more widely in medical practice. Service users value an holistic or combined approach which takes account of both the individual and their social circumstances. Findings highlighted the complexity of service users' views, their reluctance to impose monolithic interpretations on their feelings and experience and desire to take account of both personal and social issues.

While some service users value some medical interventions, they draw a distinction between that and a narrow medical model and over-reliance on medication. While seeing benefits to be gained from social approaches to mental health, particularly for members of black and minority ethnic communities, they also see practical obstacles in their way. Most service users involved in the project strongly support the idea of developing discussion about social approaches to mental health issues, particularly among service users/survivors. Some feel that progress is already beginning to be made and that there is more preparedness to think in such ways among some mental health professionals.

6. A key part of this project was finding out from service users how they felt more social approaches to mental health might be taken forward. They offered many ideas for how this could be achieved. In a number of cases, they raised issues which would both encourage a shift to more social understandings and which would also benefit from such a change – cause and effect were closely inter-related. Their ideas included:

• Incorporating such social models and ideas more in professional training, education, practice, policy and research, as well as the media.

• Service users having more opportunities to get together, as in this project, sharing their ideas and experience, gaining confidence in their views and building links with supportive professionals and other potential allies. Some see more user involvement in research as helping to develop more social approaches in services and support, by including lived experience and experiential knowledge.

• Giving greater priority to the funding of mental health policy and services, while also redistributing funding to ensure that smaller user led and community based initiatives have fairer and more equal access to funding. Service users see more social approaches to mental health and increased user involvement

as closely interlinked and argued for funding to support such involvement to increase service users' control over their health and well-being.

• Some service users draw a strong connection between more social and more preventative approaches to mental health policy and provision. They feel that there is a need for better early interventions for people being referred to services. This could help many people avoid reaching a crisis stage and reduce both human and economic costs in the long run. Current underfunding, rationing and cost-cutting approaches ignore broader personal and social costs and the way that adequate investment could avoid these.

• The existing disability benefits system largely rests on a medical model, assessing mental health service users on the basis of what they cannot do, rather than what they can do. Service users have to demonstrate deficiency and incapacity to get support, rather than support being offered to help them to achieve their full potential. Current welfare 'reform', framed mainly in terms of physical and sensory impairments, creates additional problems and barriers for mental health service users. Some participants highlighted the importance of replacing a system which does not readily recognise 'hidden' impairment like theirs, with one which instead values people experiencing distress and their potential contribution, for example, through voluntary work and community involvement. A benefits system based on a social approach would reduce rather than reinforce stigma and the negative stereotyping of mental health service users and challenge rather than add to the hostility and discrimination they face.

• Service users highlight that the narrow focus of a traditional medical model of mental health, with its emphasis on the individual and personal pathology, significantly fails to address cultural and ethnic differences. More social approaches both encourage recognition of such issues and an anti-discriminatory approach and are themselves supported and advanced by this.

The Report offers a series of recommendation for taking forward more social approaches to and understandings of mental health/mental distress.

INTRODUCTION

These are highly contradictory times for mental health policy and services in the UK. Mental health seems to be high on political and media agendas. An important new idea, 'recovery' has been prioritized in mental health provision. This emphasizes that people with mental health problems can recover and play a full part in society again and should not be written off.[1]

The government has committed itself to 'parity of esteem' for mental health alongside physical health care. As Deputy Prime Minister, Nick Clegg made a commitment to 'end discrimination against mental health'. For the first time, access and waiting time targets for people with mental health problems have been scheduled as a first step to ensuring mental health services have the same priority as those for physical care.[2]

At the same time there are widespread concerns that there is a worsening crisis in mental health provision. The Care Minister, Norman Lamb has said that services for children and young people are 'sometimes completely unacceptable'.[3] High profile campaigns like that in Norfolk and Suffolk have repeatedly evidenced breakdown and crisis in funding, community services, personal budgets scheme, crisis team and in the availability of mental health beds for those who need them, with service users sent great distances because of the inadequacy of local provision.[4]

At the same time, more fundamental questions continue to be raised about mental health policy; its preoccupation with diagnosis and drugs, the increasing use of compulsion, the large numbers of mental health service users in prison, the low numbers in employment and continuing high levels of suicide and self-harm. Yet there has long been particular interest in the field of mental health in the involvement of service users and there are now hundreds of local groups and organisations of mental health service users/survivors.

In these complex and difficult times, the aim of this report is to try and look beyond current crises and draw on the views and experiences of mental health service users/survivors, to identify more hopeful directions of travel for policy and support building on their first hand evidence.

1 http://www.rethink.org/living-with-mental-illness/recovery/what-is-recovery
2 http://www.independent.co.uk/news/uk/politics/lib-dem-conference-nick-clegg-pledges-to-end-the-shortfall-in-mental-health-treatment-9780887.html
3 http://www.libdemvoice.org/norman-lamb-writes-improving-mental-health-services-for-children-and-young-people-43271.html
4 http://norfolksuffolkmentalhealthcrisis.org.uk

BACKGROUND

In 2010, the Joseph Rowntree Foundation published the findings of a national project exploring the views of mental services users/survivors and disabled people about how they felt mental health issues were understood in society and how they themselves understood them.

The project, *Towards a Social Model of Madness and Distress?* focused on four key areas:
- How participants felt mental health issues are understood by professionals and public;
- Their personal understandings of mental health issues;
- The social model of disability in relation to mental health;
- A possible model of madness and distress.

The findings revealed that most people felt that a medical model dominated both public and professional thinking. They felt that this was stigmatising and unhelpful and that further discussions about social approaches to mental health were needed. The project also highlighted the complexity of mental health service users' own views about applying a social model of disability to mental health issues and whether they thought framing discussion in terms of madness was helpful for mental health service users/survivors.

Following the publication of these findings, the Joseph Rowntree Foundation agreed to support a second stage of the project. Its aim was to undertake a further broader consultation with mental health service users in order to disseminate the findings in a focused way and explore these with them in more detail.

The objective was particularly to reach a diverse range of mental health service users, including both those who have tended not to be involved in such discussions, as well as those with more familiarity and involvement in them. Building on the findings of the first report, the aims were to:
- check and explore service users' views of a medical model of mental health;
- find out more from them about social models and how helpful or not they see reclaiming the word 'madness', in helping to move on from a medical model of mental health;
- discuss findings about the social model of disability as applied to mental health and to explore its possibilities further;
- find out how mental health service users/survivors think the idea and policy of 'recovery' is working;
- explore how people think we might move forward with social approaches to mental health.

How we carried out the project

Participants in this project included a very wide range of mental health service users/survivors. They included people who were and were not involved in or affiliated with service user groups as well as service users/survivors who worked in mental health services, with a broad range of experience and views. A total of 82 people took part in the second stage of the project. They took part through four group discussions, eight individual interviews, and through an on-line survey, according to their preferences. The diverse range of service users who took part included, people from rural and urban areas, older women and people from black and minority ethnic (BAME) backgrounds. We were aware that there were limitations to the study as we were not able specifically to include younger people or people identifying as lesbian, gay, bisexual, transsexual and transgender (LGBT). Despite efforts in contacting organisations working with young people, we found access to be a barrier. A more detailed account of the breakdown of participants is provided in Appendix Two. The project, like its predecessor, adopted a user-controlled/survivor research approach, employing principles associated with such methodology. It was undertaken by the same team as the first stage project – survivor researchers, Peter Beresford, Mary Nettle and Rebecca Perring, this time with the additional help and involvement of Jan Wallcraft.

How this report is organised

This report is organised in six main sections. All 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 highlight the first hand views and experience of service users themselves.

The six sections explore mental health service users'/survivors' views on:
- a medical model of mental health
- reclaiming the term 'madness'
- the social model of disability as applied to mental health
- the idea and policy of recovery
- social approaches to mental health
- taking forward social approaches to mental health

This is followed by a final section which pulls together the findings from the project and offers a set of possible ways of taking them forward. There are two Appendices. The first provides a copy of the schedule that was the basis for both the individual interviews, online survey and group discussions that were carried out, and the second a breakdown of the demographics of the people who took part in those.

The labelling and stigma following from a medical model of mental illness emerged as major barriers for mental health service users.

VIEWS ON A MEDICAL MODEL OF MENTAL HEALTH

In the first stage of this project, three key findings emerged in relation to the medicalization of mental health issues.

- Most service users believed 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 saw such a medical model as damaging and unhelpful.
- The labelling and stigma following from a medical model of mental illness emerged as major barriers for mental health service users.

The same overall picture emerged in this second stage project. Most people still felt that the public and professionals interpreted metal health issues through a medical model as a medical issue. Speaking of professionals they said:

> Yes, I do. I think on the whole professionals definitely see mental health in that way.

> Yes that's why they believe in the medication so much.

> Too much emphasis is put on purely medicating without looking at the alternatives and possibly reducing the amount of meds prescribed.

> Yeah I think I agree…because a lot of GPs, General Practitioners, have this tendency to think that the medication is the key to solve all issues, rather than even trying to look at what the person is actually going through, and actually understand them as a person…

Many service users and survivors seem to feel that professionals and the public still view mental health in terms of there being something wrong with an individual:

> I think it's not just that it's located within the individual it's more that the medical perspective is that there is something medically wrong with you, hence the chemical imbalance myth.

> It's like what they do with…alcoholic treatment you know they're going to spruce you up, get you fit and then you know shove you out the other end and you'll be fine.

Many participants framed their answer in terms of medication. They associated reliance on a medical model with an over-emphasis on drug treatments:

> …I haven't dared tell my daughter a lot [about my] mental distress because I know that she will want to look for physical things that are wrong with me.

> Yeah because that's what we are lead to believe, that's what all we're taught. They don't even give an alternative, they just assume that if get dragged up from the street, or the house by the police, or whoever, or by GP or…a social worker, that there is a problem with you and that it is a medical issue.

> I think that public attitudes are shaped by stereotypes that have developed as a consequence of the medical model. I think that public attitudes are shaped by the opinions of professionals, who are commonly held to be the experts in the field.

Although we asked specifically about professional and public views, many people also talked about the views of their family. From their responses, it appeared that they saw public and family beliefs as more complex than professional ones, shaped by medical, cultural and sometimes social ideas. These comments reflect the rang of opinions that emerged:

> Some members of the public do see mental health issues as medical, but others see it as the opposite. The "pull yourself together; there's nothing wrong with you" attitude is still prevalent – especially about anxiety and depression, OCD ('obsessional compulsive disorder') etc..

> I think the public...I think they hold two views in parallel. So I think there is the view that it's like a broken arm if you get depression or something, I think that's one idea that people have. But I think they also have an idea that you get depressed because you're bereaved or, you know, something happens in your life, so I think if you've lost your job or you had a difficult childhood. So I think the public holds both views in parallel.

Some participants thought that the public view mental health as linked to medication. They have the view that if someone is not taking medication then either they should be, or they are not unwell.

> When I was recovering from my depression I was doing it on my own. I had approached my GP who said, 'Do you want to take medication'? I said, 'No I want to stay clear of that'. Um a couple of years later someone said, 'You know you're 'depressed?', I said 'Yeah', they said, 'Are you on medication' I said 'No', You can't have depression then'. So there is an automatic assumption that you've got to be medicated if you've got depression and if you're not, you haven't got depression.

Other service users felt that the public did not necessarily believe people were distressed unless they fitted their stereotypes.

> I think that the public don't necessarily see mental health problems as a medical model as they may disbelieve them since invisible. This definitely applies now with the culture of stigmatisation of benefit claimants.

Internalising the medical model of mental health

The findings from this second stage work, confirmed our earlier finding that it is common for mental health service users/survivors themselves to accept and internalise a medical model of mental health. Most service users/survivors agreed that they had at some point come to believe in it. They said that this was due to the prevalence of the medical model within professional practice and thinking and also beliefs held by their family.

Many people involved in this consultation said that they had at some point believed that there was something 'wrong' with them.

> Taking my own experiences into account, yes, I would say that it is a common belief that the origin must be in the mind and so needs a medical solution.

> Yeah, I think there is a tendency. Especially, I mean I used to have a big alcohol issue as well, and well you know, nearly everybody internalises that because it is so shaming, especially for a woman actually, you know. So, yes you certainly internalise it. And yeah, you know, and it could even be kind of self-perpetuating if that the right word, because if you're internalising being seen in a particular way then you start acting in that way as well – you could do, you could do.

They talked about internalising a medical model because it is the predominant model within the mental health system.

> I think the options that are given are what else am I supposed to think and it's kind of rare to think otherwise if you're really that strongly against your diagnoses. But if you've been told by professionals that this is what's wrong with you, this is the medications you need to take, then that's it really isn't, you get on with it really.

> Well I think that it can be useful to have a diagnosis, and then to be treated with the appropriate medications. But, this is only part of the picture. And that if you are taught by everyone that the medical approach is the only way, then of course people will accept this as the status quo.

Some people said that being treated within a medical model meant that they did not realise that they were internalising the medical model, until things began to improve for them:

> I do think that it's really strongly still a medical model in society in the way that people are treated…And I think it does lead into them…you end up pathologising yourself in some ways. I don't think you realise you do it until you start getting well, then you start to question some of the approaches and some of the experiences that you've had with some of the professionals you may have worked with….

Participants spoke about how they felt pressured to internalise the prevailing model of mental health because of the way the medicalised views of professionals are endorsed by the wider society.

> I think that the pressure to accept and internalise the medical approach to mental health can become relentless. This pressure is often exerted by family members, mental health professionals and wider society…

> I think there's pressure if you've got your family and friends and health care professionals and the media feeding this message that it's like a broken arm and you're just 1 in 4 and it's a medical issue, then I think it's hard to resist that. People might be confused about the role of social factors in their lives, or the role of social factors might be denied or down-played by their families or by others.

A small minority of participants took the view that believing in the medical model can give people reassurance. By thinking they have something 'wrong' with them people can feel that they are not to blame for their actions or it can offer a reason for why they feel unwell.

> People might feel some sense of relief if they can think of it in terms of a medical issue…people might find it helpful to think 'Well it's not me, it's not my fault, I haven't done anything wrong'. So I think that might be another reason why they accept the medical view…The other thing I thought that it might resonate with people, they might think, 'Well nothing bad had ever happened to me, like I lost my sister when I was young or I lost my job, these things have happened but they're not that bad, other people have much worse, I don't understand, this doesn't make any sense'. So it might make more sense for people to think about it in a medical framework as well.

> And I think also for some people I think it's a bit like being given a 'get out of jail free card' because you're told, and I've read some really interesting stuff by a survivor on this issue, I can't remember his name but he said that, when he accepted the medical model he said it was brilliant. When he was in hospital he said if he wanted to just pick up a chair and throw it through the window he did because it wasn't his fault, it was his illness. And… he said the hardest thing for him was learning to accept responsibility, and that meant…that meant not using illness or the medical model as a licence to act as he pleased, but to learn to take responsibility for himself and to understand himself and his emotions and his feelings in a different way, and in more responsible ways. So I think there's that issue as well.

The damaging and stigmatising effects of a medical model

Most service users confirmed our original findings, seeing a medical model of mental health as damaging and stigmatising. They had a lot to say about this. Most people thought that it was, but a diverse range of experiences and reasons for this were discussed. Most participants talked about damage and stigma in relation to the psychiatric profession and psychiatric practice.

Many felt that a medical model continues to dominate professional thinking and practice through professional judgement and decision-making. By holding power and knowledge, professionals make decisions and judgements about service users. Many felt that no discussion took place between the professional and the service user. People were not listened to. This was damaging to service users because it took control and decision-making from them.

> A lot of them just believe in themselves and they are guarding themselves. They are superior and what they say goes, and what you say doesn't really matter. 'I hold the key, I hold the what is what', and that's all they all want to believe.

> Experiencing mental distress is frightening. Frightened people need care and support to rebuild confidence. It takes strength and resilience to come through. Medical people believing they know more about you than you do is very frightening.

> It is not that I believe the medical model is a bad model, it is the overwhelming use of it within the mental health arena which has a significant contributory factors to perpetuating myths and stereotypes of mental ill health. Further, it encourages the medics not to examine their own personalities and points of view, as it closes down discussions around ideas of

'madness' and tends to give this experience no value. Additionally, it places too much focus on utilising medicine and other forms of 'treatment' to the person. Whilst the latter treatments can sometimes be of benefit, in comparison, hardly anything is done about assisting people to come off and/or reduce their medication safely and informatively. Thus again perpetuating myths and stereotypes of individuals with mental health difficulties as 'weak' or 'damaged'.

Service users/survivors felt that many professionals do not relate to or listen to service users, perhaps because they have no shared experience or understanding of what happens to them. There was much discussion about the issue of professionals not listening to them, as the conversation below demonstrates:

> It's not listening to people as well [that is a problem] because for some people it is better [to be on medication]...I mean I've got a friend who feels like she does need, weighing up her options, she feels she's better on than off. But its not having that control over that decision, not being given all the facts and then making a decision about your own life. It's not having the power to prescribe yourself stuff.

> or being offered alternatives. There are alternatives...

> yeah.

> ...they're just not spoken about. I mean I work more and more in human rights and I will never say to someone, 'don't take medication'

> – it's completely your choice. But by the same token, don't force me to take them if I don't want to take them.

Others said:

> ...they don't listen to our needs. They want us to act when they want us to act, they want us to think when they want us to think. If you go

outside the box you are different and that's stereotyping, you know. Because I have witnessed it from the last relapse they don't really listen to your needs. You have to tell them exactly what they want to hear or you're not getting out of there.

Some participants spoke of judgements being made about their state of mind by professionals who do not know them or see them regularly.

the medical model does have problems because when you do see a psychiatrist, or a CPN (community psychiatric nurse), or your GP, it could depend how your mood is and how you're feeling. So for that 15-20 minutes you're seeing them they don't know how you were for the past week or two months and they think they can say to you – which isn't exactly scientific – 'Oh you look alright today', which means to me, it means that's like an insult because a patient could be suicidal 20 minutes ago and there's no scientific test to prove how ill he is, and it's their judgement for that 15 minutes and what they write about you .

You've got these people who are supposed to know about you and they know nothing about you whatsoever. They are just going by what notes they have got in front of them, and they have already pre-judged you as to what your problem is, what the solution is – medication.

Many people felt that the medical model is still prevalent because it is so ingrained within medical practice that it makes it difficult for service users as well as professionals to challenge it.

My sense is that the dominance of the medical model has generated particular approaches and responses (for example, reliance on meds) which frames how professionals respond – whether they actually believe it or not – the system is firmly framed in a medical view and as such other options are not readily available to professionals.

I think that professional attitudes are dominated by the medical model, to the extent that it becomes almost impossible for professionals to see mental health in any other terms whilst continuing to pursue their profession. I am aware of former professionals who have chosen to adopt a different career path (for example, lecturing, research) rather than continuing to work within the medical model dominated mental health industry.

Many people were concerned about the relationship between the pharmaceutical industry and mental health system. Some participants strongly felt that the influence and power of the pharmaceutical industry creates an over-reliance on medication as treatment and is a reason why challenging it is difficult, when profit is linked with medication.

It's a big business with the pharmaceutical companies and no matter what you do, they want to be making money from the medication – that is the way I see it, it is a big business. It doesn't matter what you do, it doesn't matter what you say, the whole idea of sectioning people is also to experiment with the new drugs that are coming out. So to me it's more complicated, it's an evil business.

When medication is being used in psychiatry widely, it is very often being promoted by someone making money out of it. Those are the problems and key things that I think we need to [recognise].

Medical language was also identified as a major problem. Some service users talked about the language and definitions that were used in relation to their diagnosis. They spoke of professionals using language which service users often didn't understand. For example:

...the language that they use, I mean they've got all this technical language, and you're sitting in front of them and they're talking about you,

it's like you're at a lecture, there's some serious, serious vocabulary that the ordinary layman cannot understand. They make a clear distance right at the beginning, you know, power distance like I am superior you know by using that language...

...absolutely.

it needs to be more user friendly the language.

Mental health service users/survivors also talked about how the over-reliance of drugs within a medical approach could be damaging.

This is the serious issues of service users – because I've been on medication now for maybe about 12, 13 years – and I've never once heard a doctor say, 'I'm going to give you a review to see if there's something else'...And I got unwell (from medication) and I got unwell until it was to such a point where I probably wanted to die, because before this medication everybody knew me – I was...I was able to work, I was still able to be a mother, I was still able to enjoy certain things of my life that I had and the medication prohibited me from doing that...So it's like a pole vault and if you're not really strong and empowered to tell them, well I'm not going to take this one because this made me feel...If you're not strong you could just be taking your medication to cause you to be like this.

It's actually these drugs – anti-psychotic drugs, you know, millions of people are even being forced to take on community treatment orders, are causing people to be dysfunctional and ill.

So I have to live with this every single day and live with this reminder with the drugs every day, and the side effects are obesity and then with obesity you get diabetes and hypertension and gout now, and problems with your eyes. It's ridiculous it goes from one thing to another.

Most service users who took part said that they felt the diagnosis and associated label attached to them were damaging and stigmatising because people viewed service users in terms of their diagnosis, and thought of them narrowly in terms of behaviour associated with such labels. Some felt that these labels often distort public understandings of mental health issues.

I think that if mental health problems are seen as an 'illness', which can only be dealt with medically, the effects are that people's real needs are disregarded. Once the medical model is applied, then actions are attributed to the 'illness' and anyone with that diagnosis is then seen as capable of certain actions because of the 'illness'. People are seen as the 'illness' – the person behind the diagnosis gets lost.

...the reason why a lot of people relapse and end up in hospital is that they don't have a social network when they come out of hospital. And it's hard to socialise with people especially if they have thoughts about you – 'Oh he's schizophrenic', they go on the computer they type in schizophrenia – 'Oh they can be very violent, they're this, they're that'...so you can't find people who will associate with you because they see you are tick, a time bomb to the public.

...I fought for a long time about my diagnosis, schizophrenia, because I thought it is the worse label they can give a person. And they give it to many black people, to black men in particular, and it's next to pathological, psychopathic killer. And it's not at all helpful, it's very negative connotations as 'mad, bad and dangerous' and a 'psycho' and that you're a risk to the public or that you are a risk to yourself.

Firstly from the public point of view...this is taken to be sign of madness, certain people to be kept away from or not to be approached, or deemed dangerous or can cause harm.

And as this discussion highlights:

> I think labels are dangerous. If you're labelled, then it's very focused on that label rather than the picture as well.
>
> Yes.
>
> And I think the public, people in general, tend to see mental health in the same way.

Service users/survivors who took part, talked about the isolation that they experienced in their communities and cultures as a result of such attitudes and beliefs around mental health, together with racism and stigma from the public. Comments like the following highlight people's strong sense that cultural and societal beliefs about mental health play a large part in how it is seen and how people are treated resulting in stigma and damage to service users/survivors.

> Stigma is huge, massive...And the derogatory terms just from our own culture as well...being insane, being mad, being crazy, that comes from our culture, but then we have it in my work culture, I've heard people say things like looney bin...and a few picnics short of a basket and all these things in our everyday modern culture as well. So...stigma is very negative.
>
> I think that there seems to be double discrimination, for example, with BME communities because of the stigma, it's even more so within those communities. And then you've got the stigma with the general society and the racism as well...
>
> Some see mental health issues as spiritual. When I first became mentally unwell many years ago, certain people from my then church told me this was 'sin' – thus making me much worse as I then had huge guilt feelings...This appalling attitude still exists today amongst some religious people – including the belief that mental health problems are caused by 'demon possession'.

Service users/survivors had a lot to say about why their family and friends saw mental health difficulties as an illness. One reason they gave was that beliefs are underpinned by fear. Participants felt that family may be fearful that 'mental illness' may happen to them. By seeing mental illness instead as a fault within the individual family feel reassured that their relative can be 'fixed' with medication.

> And I think one of things that I've encountered has been a complete refusal in people in my family to recognise that's there's anything wrong with me, which isn't to do with having a warped personality...They basically, definitely 100 per cent see it as something the matter with me...Perhaps they feel safe if they see it in that way, maybe if they look at it as it really is – [what] it actually [is] – it can be anyone at all and it can come and go, it can go completely or it can be a phase you're going through. If they start to see mental health or substance use like that, that's much more frightening It could happen to them and they don't want that. So perhaps it's safer to put it in a box and that's tough because it's your life that gets mangled in the process.
>
> Those of us with mental health issues represent some of the most frightening aspects of being human We literally embody things people fear at a profound level – unreason, challenge to social contract, highlighting issues people can't tolerate such as the futility of living, familial abuse, vulnerability to violence and mortality. What better way to wipe away these fears than by locating them in a 'broken' person rather than acknowledging them as consistent, frightening features of society – and so the medical model acts as a kind of comfort blanket obscuring these bigger issues from view.

Some participants talked about their family members wanting to find a 'cure'. If a parent can see their child's mental health problem as lying within the child, then, however unwarranted, they may not have to feel some sense of guilt or responsibility.

> I think one of the difficulties about the medical model is parents' attitudes. Because for parents who have a child who has mental health problems it's a really safe place to go. It's outside, it's medical...

> Because they don't want the guilt, they don't want it to be a social thing that they had any sort of cause or factor in, and they want to be able to stop [it]...They just desperately want a pill or a cure or a gene theory or a brain surgery or something that will take away their responsibility. I mean they can die and 'little Jonny' can be cured and get on with, you know, a perfectly normal life because he's got the right pills.

> Family/carers are the people least likely to want to know about this. It's much more comfortable if their relative has a medical condition, and not something that they can make better or worse by their own behaviour.

Service users/survivors also talked about media representations reinforcing public beliefs. They reinforce stereotypes about mental health feeding into the popular fears and ideas about people with mental health problems, as this discussion reflects.

> ...and media representation of mental illness is just disgusting as well.

> it's ridiculous.

> it hasn't helped at all has it?

One service user said:

> it's also damaging because as soon as you hear in the news that somebody attacked their partner and they find out that probably that person has suffered with mental health issues, so they see the media...broadcasting [that].

> So it's like the public sometimes they become fearful of people with mental health...all sorts of people suffer with mental health, it doesn't mean that they're going to go outside and kill somebody you know, because everybody suffers at a different level of an illness. But because of how it is glamorised in the media it gives a perception that is quite negative.

Challenging barriers, discrimination and stigma

Participants had many ideas about how to draw attention to and challenge the barriers, discrimination and stigma mental health service users/survivors experience and the ways in which they are excluded from areas of society and social life.

Some felt that it was essential that the medical model within medical practice was challenged, because of the key role they felt it played in shaping wider understandings of distress.

> Psychiatrists [have] ultimate power with service users, so they need to be targeted to get them to change their heavily drugs related approach which is of course backed by the pharmaceutical Industry. I don't object to honest attempts to treat people's mental health conditions by medical means...but I DO feel that there is a level of dishonesty in the way this has been done over the past 50 or so years. The excuse given for doctors pretending to know more than they do about mental illness is that it 'reassures' the patient – but in reality it has a lot to do with maintaining the medical power base. I don't mean that doctors are doing this on purpose...rather that they have fallen into a questionable belief system. I do accept that there are certain mental health conditions whose immediate causes lie in a malfunction of the brain. Unfortunately, medical science does not yet know much about what causes these conditions!...How can we persuade medics to be more honest about how much they don't know?

Some participants emphasised the importance of campaigning as an effective way of trying to change attitudes and inform people about mental health issues.

> I mean the first thing that's got to be changed is the idea that mental health service users are likely to be more violent than any other member of society. It's just not true…and it's ridiculous that it's still believed…

> Keep being involved in whatever campaign, work or initiative that is going on as best as one can. Keep plugging away as part of everyday activity.

Some participants identified education as a key area to help change attitudes. To be effective, children from an early age need to learn helpfully about mental health issues. As participants in one group discussion said:

> Talking about education I mean it would be good if things like mental health issues were actually discussed in schools…

> Yeah.

> Yeah.

> …to raise awareness nationally of mental illness and I think we'd have a more sensitive society then.

Other service user/survivors said:

> …I think it's one in four…people will have some mental distress at some point in their lives. Yet in school people would think that anybody who had mental health problems – they'll probably have a few Goth friends – and the rest they'd say they're the nutters. So something at a school level needs to be addressed I think. Just so you know that having mental distress is part of normal life. That we all get mentally distressed when certain circumstances are too much for us, and it's getting that message across in schools I think so people aren't just like 'Oh she's a weirdo'.

> Yeah and trying to get quite small children to value adversity. Because they don't. That's the last thing they seem to do.

> …if we could think of small posters that were effective and have them say on the Tube, um, do you know what I mean, places where people pass by and notice things. In free newspapers on the buses and trains where people are sort of stuck there – doctors surgery's where people get to hang around perhaps because they don't want to and then they perhaps pick up something they wouldn't normally have picked up.

Participants saw the media as key in tackling discrimination and stigma. But some felt that the media instead still often reinforce negative ideas about mental health and this needs to be reversed.

> More coverage of a range of mental health issues including PD [personality disorder] – and the way this stigmatises and limits people. Truth in the media about the challenges we do face, i.e. people aren't shirking work.

> Media coverage, real case studies perhaps – though many people are afraid to speak out. A lot of press coverage is unhelpful, for example, fantastical benefit fraud stories which should be regarded as a rare event, get front page treatment.

> I think the media need to realise that they need to have a better understanding of mental health. They can't just label everybody under one label. That they need to show that – actually tell people, actually know people – have different illnesses that not every person suffering with it is a violent person. But the media needs to get that across to people. Otherwise people just judge everybody.

They also raised the idea of television programmes as a way of getting people to think differently about mental health issues, building on developments that are already taking place.

...Soap operas and things like that are a really good way of educating people. And sometimes they do things quite well... Suddenly they do something on child abuse and everybody's reporting things that have happened to them years and years ago because they've been given permission to do that. I think that there's a lot that should be done in all media.

I do agree but you've got the have the right attitude to start with. I mean some of the things that have been done about alcohol in soap operas are really unfortunate.

The alcohol stuff on TV is really bad.

Yeah, yeah.

And it's always blaming the person.

Always, yeah. They never, never – and what an opportunity the soap operas would have had – to explore the issue properly but they didn't.

The same thing goes for *EastEnders* – [they've] have been peddling the bi-polar stories but every time the character becomes unwell or is unsure, whatever's happening – 'Have you been taking your medication?' – that's the first line! You know it's about the different realities. The public can't handle this reality at half past seven in the evening, watching the box and eating their dinner at the same time – I do that, I mean I'm not putting Joe Blogs in there, I do that as well. But you know, they're not prepared to listen to a different story around being bi-polar, or whatever that means actually.

The media is beginning to show an interest in mental health problems and often have their mental health 'seasons'. It would be good if those who have the right contacts could persuade them to run a series of programmes on this. It would then give the credibility for activists at a local level to start challenging the system, as it's very hard to have those sorts of discussions and get anywhere.

You know that 'free speech' that goes on channel 4 I think it is, once a month – things like that, have it discussed there. Or have a programme teaching about it, you know, not late at night two o'clock in the morning like Open University like they normally put them on, but like eight o'clock, nine o'clock. Something like that. Have it open for discussion, have young people talking, have older people like myself talking, and children of people like myself...They could talk about what it is to have a mum or dad who is mentally ill.

People talked about how different media could be used to help in campaigning.

I think social media is a great way to reach a lot of people.

The role of individuals with personal experience is fundamental in this regard- sharing their narratives. Media campaigns, newspapers, television – social media all have a role in challenging narrow, medicalised approaches.

Through the use of social media, Twitter and Facebook.

Some service users/survivors thought that the idea of using celebrities and successful people could help to break down barriers with the public.

It would be good if 'successful' people who have mental illness were open about it.

I think it's been quite important how celebrities have come out in recent years and you know, recognise the fact that one in four people will suffer mental illness...and not regard those suffering with chronic depression as some sort of weirdo.

In the media we are getting to the point where celebrities are [talking about their mental health]...and I think that is helpful and a good thing because it reduces stigma.

> Well I really like the idea of advertising ourselves. I mean a survey is good, but I really like the idea of advertising, advertising, advertising! Finding the people who will do it and the public will take a shine to – and go for it.

Participants had a lot to say about anti-stigma 'campaigns, notably 'Time To Change', the high profile government sponsored initiative which has been led by the big mental health charities. 'Time To Change – let's end mental health discrimination' generated very mixed views. Those who were critical of it, felt that it operates within a medical model, which perpetuates public's misunderstanding about mental health issues.

> The trouble with anti-stigma campaigns like Time to Change is that on the one hand they accept the illness model, then try to change public perception about it. But we need to get rid of stigma at source by getting rid of unhelpful diagnoses. If we had an accurate version of humans which pinpointed the central question as 'what can we do about human suffering?', then we'd be on our way to ending stigma once and for all!

> But I think worryingly it's the medical model which is starting to dominate, I think...and I blame 'Time to Change' for that. I think it's pushing people more towards the more medical side of things. And the one in four statistic, I think that's not helping as well.

> We need to be cleverer with our campaigns on the TV. They're a bit wishy washy some of the stuff – some of this so called anti-stigma. I think the English ones and the Irish and, you know, whatever, they're all a bit wishy washy. They sort of reinforce stigma, the so called anti-stigma campaigns. They don't go to the heart of the matter which is the psychiatry and the labelling of people and the diagnosing...We're going to have to shift the system and the culture and that will effect, you know, that will reduce the stigma.

On the other hand, some service users/ survivors felt that 'Time to Change' was doing some good work, but it needed to be led by service users/ survivors.

> We need to continue to build leadership within 'Time to Change' by people with lived experience, and to tell more hard-hitting stories about the reality of the barriers, stigma and discrimination we experience. Having said that, we need to take the public with us, and negative campaigning all too often results in people switching off from the subject altogether, so we need to get the balance right.

> I think that this ground has been largely co-opted by the 'Time to Change' campaign, which is widely acknowledged as the bona fide initiative charged with working in this area. Whatever the merits of 'Time to Change', I think that awareness raising and discrimination challenging work as it pertains to mental health, should be developed, delivered and led by people with personal experience of mental distress.

> Link in with the TTC campaign and other campaigns on these issues and possibly cross-disability. I think this is happening already on some topics.

Others felt that 'Time to Change' was a start and should be seen a campaign that could be built on:

> I mentioned before I'm a supporter of 'Time to Change', which as well as Facebook and Twitter campaigns, has started advertising on TV and pushing TV dramas to include mental health storylines and characters. I think 'Time to Change' focuses mainly on combatting stigma, but a similar model could be followed.

Although I'm critical of Time to Change's reinforcement of concepts of mental illness, I also think it's been good to have a big, visible, active national campaign. I think this should be on-going.

It was clear that language and meaning were very important to people, highly contentious and that there was no consensus.

RECLAIMING THE LANGUAGE OF 'MADNESS'?

In the first stage of the project, while participants were generally unhappy with a medical model, they were also wary of non-medicalised terms like 'madness'. Views about this were very mixed. This could make discussion difficult and had helped to discourage it. Given the international emergence of 'mad studies' and the publication of a key text associated with it 'Mad Matters' since the first part of the project was published, this issue seems likely to have gained even greater significance (LeFrancois, Menzies, and Reaume, 2013).

The same picture emerged in the second stage of the project when we explored terminology with mental health service users. The words 'mad' and 'madness' continue to divide opinion. People had very strong views over whether reclaiming the word could be helpful. Some were happy to use the term and had identified as 'mad' at points in their lives. Other's felt that they would not use it personally, but believed that it was up to each individual if they wanted to use it or not. There were also many people who did not think it was helpful or could be reclaimed, or who disliked the term because it had a very negative meaning for them. It was clear that language and meaning were very important to people, highly contentious and that there was no consensus.

First, we hear from participants who felt that the term could be reclaimed. They felt that it encompassed their experiences well and was empowering.

Yes, I'm fine about madness, I mean I sometimes use it...I think for me I'm quite happy with 'bonkers, mad, daft', or any...'off the head', I quite often say 'doolally' or I was 'off the head', and people do get a bit offended by these words and I don't. We need to re-claim them. That's the way I see it and the mental hospital, being a mental patient, I think that's OK to say that. But I've been wrapped over the knuckles for things in Scotland at so called recovery events for using these words...

I much prefer the word madness to describe my own experiences and that of other people – to reclaim the word madness for ourselves is empowering.

Language is a very powerful tool. It has a subconscious effect on framing internal concepts and schemes. Reclaiming the word and using it in a positive way could be a very empowering. The gay community have done this very effectively with the word 'queer'. I embrace my madness and do not suffer my insanity. It is an important part of my identity. It allows me to see the world differently from

others. I have often been chided for referring to myself as 'mad', particularly by medical professionals. 'No one is mad anymore', they say, 'It is not politically correct'.

Most participants, however, had reservations about the term. They were concerned about the different meanings and ways in which the word is used. They were uncertain about how successful reclaiming 'madness' could ever be. Some talked about how they would use it in certain situations and with other service users. Most would not use it in wider society because of the many different, often negative meanings, associated with it.

> …I can kind of understand why that's come about that people have been saying lets reclaim the word because lots of different people have done that. You know, a word that was negative and let's reclaim it and use it for ourselves. I think it's alright if you want to do that if you're with a group of other people who've got similar experiences. I think to kind of like be reclaiming that word for when you've got an appointment with your consultant or when you've got an appointment with your CPN and stuff there just isn't that kind of dialogue generally with them. You know you might – somebody gave the example that they got on better with their social worker, you know, you might come across the odd person who is willing to kind of explore things in that way, but most people who work in that profession aren't for whatever reason, whether its caseloads or whatever. You know, so I don't really see how that would be positive on a wider scale really.

> I use this in my language from time to time with learned colleagues. It also aptly describes the turmoil I can experience when in distress.

People also thought that there is a risk of romanticising the word, when madness can be a negative experience for many people.

> …I mean I don't mind calling myself mad or I have been mad, and I can see for example 'mad

pride' and the attempts to actually reclaim this word and sort of celebrate the, you know, the courage and the survival. But on the other hand I think sometimes through all this madness discourse there is romanticisation of mental illness – of mental distress sorry, and I think that is not necessarily very helpful. So yes, reclaiming the word is helpful but I think going to, um, the kind of sometimes extreme of just emphasising the, you know, triumphant and sort of celebratory notion and aspect of the madness thing, I think it's half the story because I think there's a lot of suffering and a lot of negativity around the experience of mental illness.

> I understand the intention of "reclaiming" language and concepts and "turning them around". I admire the attempt to do so. However, while some people may be "mad and happy", for others their madness is terrifying and can never be something they feel positive about. I know for example, some voice-hearers are happy with their voices, but many are not (they have told me)

Most participants felt that the term madness had no clear or agreed meaning and that this undermined the value of trying to use it.

> I think one of the problems is really because we use the term all the time – it's mad, it's madness, it's crazy – there's so many possible meanings and experiences attached to it…how is it going to help us reclaim some ground? I'm not sure because it's used by everybody in lots of different ways.

> It might be for some people, for me it's a non-issue and survivor time could be better spent. Nowadays I more frequently hear the word associated with risk-taking activities (dangerous sports) or people engrossed with time-and money-consuming leisure activities (meaningful activity which supports their mental health!). I don't remember when I last heard it in general use for mental illness – perhaps a historical

documentary – the media again. Words change their meaning over the years.

I'm not totally sure that by reclaiming the word madness helps with this – what do we mean when we use it? The general public has their own notion of what it means – and it implies something which is deranged /irrational – surely we are not wanting to convey that that is who we are. Where does that help us to move on?

Some service users/survivors felt that using a word with so many different meanings and connotation's would exclude and divide service users.

What is 'madness'? Is it the experience of being out of touch with external reality? I.e. what some would call 'psychosis'? If so then the term 'madness' excludes those of us whose mental health issues are depression, anxiety, phobia, OCD etc. Survivors should not exclude their fellow survivors by the language they use.

I don't feel that madness would be applied to me as I've never been psychotic. This matters in some circles of survivors and in services. I would feel excluded as I do by services, not ill or mad enough to count! For other people who have experienced psychotic breakdown, then they should be able to reclaim the word if that makes sense to them. But then it may lead to associations with words like 'nutter' and 'psycho' which get used in a negative way about people with mental health problems.

Some service users had mixed feelings and preferred to use their own words to describe their experience and how they were feeling.

People use words in ways that shift and change and have relevance and meaning for them or not. Many service users I know would not want to use such terminology [as madness] about themselves. Some people use the word mad in connection with activism like 'mad-pride' and this is another reason for using the terminology. I think people need to be free to

choose whether and how they talk about their problems, and different people find different strategies helpful. I think it is better to be permissive and supportive about the range of ways that people think and talk rather than prescriptive and controlling.

Yes and no. It should not become a new dogma. I would encourage sensitive diversity in language. Although I was amongst those who pioneered the use of the term mental distress in the 1970s and 1980s I do not think anything is to be gained by 'moving on' from the medical model in the way you suggest. The term mental distress was a way of escaping from the trap of terms like mental illness that pinned us to a specific way of understanding what is happening. It was a liberating concept. I never thought of it as providing a new cage restraining us from making use of the richness of medical narratives. I would like to see a return to the liberation mode. Similarly with madness.

No, I use the word [madness] in the context of emotional letting go…I see it as a powerful word of expression…However I do not believe that the word has good connotations in the minds of the general public or many minority communities.

Others felt that perhaps we need a new term that does not have the same negative associations.

There's so many examples of people with the resilience and the strength to get through. So instead of using this kind of word, madness, you should [use] words that bring joy, bring hope, bring meaning, to people's lives.

Personally, I am not ashamed to use the term 'mad', as it helps define us. However, it can also set us apart as different and this may not always be helpful. I was part of early days and the emergence of Mad Pride…Time has moved on with concepts, 'recovery' etc. all altering from grassroots meaning. Maybe 'mad' needs to be revisited – distress may be more acceptable nowadays?

Some participants felt 'madness' too negative a term to reclaim.

> I [think] the term will keep stigma fresh and alive. If we wish to be seen like any other person irrespective of our mh [mental health] issues, then we cannot go round claiming a madness way of life or way of behaviour etc. I am not 'mad' I have a psychiatric diagnosis that is treatable and I am in a good position where I am not in the worst part, which was many years ago. However, I still have difficult days which are not pleasant. However, I have parts of me that are very alive etc. and I just see myself as having MH issues but definitely not 'madness'.

> No. As an individual, you're entitled to use whatever terms you choose about yourself. However, I find the term 'madness' highly unhelpful, outdated and offensive and don't appreciate its use by groups and professionals. I prefer the term 'mental health diagnosis' – just because someone has been given a label by professionals doesn't mean there is a 'problem'.

> There's been some evidence of groups of people reclaiming [language]...be it black, gay, that have been pretty positive. I have to say I'm not conformable with that idea of reclaiming madness.

However as one service user survivor said, whatever language you use the predominantly negative way in which mental distress is understood in society, is likely to catch up with you.

> I think as soon as you say I've got a mental health condition madness is straight in their heads isn't it.

MENTAL HEALTH AND THE SOCIAL MODEL OF DISABILITY

The social model of disability emerged from the disabled people's movement. It draws a distinction between individual impairment and a disabling society. The individual may experience or be seen to have an impairment. However, disability is the negative social response to such perceived impairments. Disability is taken to mean the problems created by the barriers, discrimination, restrictions and other negative social responses that are directed at people seen to have or identifying with impairments (eg hostile and stigmatizing individual and institutional attitudes, inaccessible environments, transport, culture and communication, etc). So apart from any difficulties that a person may experience as a result of an impairment, they can expect to experience additional problems as a result of the societal response to it.

We asked participants what they thought about the social model of disability in relation to mental health and mental distress. We offered a definition for those who might not be familiar with this model and to avoid confusion (as in the introductory paragraph above).

In the first stage project, participants had mixed and complex views about the social model of disability and how helpful a related social model of madness and distress tied to it would be. The second stage project fleshed out and confirmed these findings about the social model of disability. The social model of

disability applied to mental health issues continued to divide mental health service users/survivors. It was clear that most taking part were happy to work with disabled people on issues affecting both mental health service users and disabled people. Most could relate to the idea of a disabling society. However, many were not comfortable with the idea of 'impairment' applied to their experience. We offered a definition of the social model of disability, but participants had their own ideas of what it meant to them. It was clear that many did not understand or were not comfortable with the language associated with this model.

Identifying with the social model

At the same time, there were some participants who favoured the social model of disability. They could relate to it as mental health service users/survivors. Thus they commented:

> I do identify as a disabled person. I didn't really think about it as not...when you've got a severe mental health disability, you are, aren't you.

> Well, I think the social model implies that with the right help and support and reasonable adjustments on the part of others people with any disability can flourish in society. And more specifically as applied to mental health it implies that the person should be treated as a whole rather than simply medicated.

> Society creates barriers that result in disability. For example, lack of wheelchair ramps creates disability for people in wheelchairs. People with mental health issues also face social oppression, lack of adequate services and so forth. When they become unwell, they often face stigma and discrimination which makes them more unwell.

They related the social model of disability to a human rights approach and a barrier-based model that could fit their experience:

> I look at your options, I am in favour of this model...From a human rights perspective to me it the right perspective in the sense that it means that I shouldn't be seen in a different way from other people in society, which means you should not discriminate [against] me on the basis of who I am, what I am, how I'm reacting, et cetera. If I commit a crime I should be treated exactly the same as anybody else.

Some participants talked about how they felt disabled by the way society is structured and operates. For example:

> ...I think I suppose when I'm feeling...if I'm struggling – yes, I do feel disabled, you know, I feel like it's hard to communicate with people. I feel that people are misjudging me, you know, I don't feel like I'm understood. So I do feel

disabled by my condition, you know...I give an example of I've recently started to reduce my medication, my GP suggested it and it was something that I wanted to do for ages, but I didn't have the confidence to do. And I was really excited that my GP suggested it, because...I've been with that GP since I was really ill, so for him to suggest that was kind of like an outside indicator that gosh you know, I am doing much better kind of thing...I tell some people and they are like, 'Oh that's brilliant', you know, 'see how it goes', blah, blah, blah. And I told one particular person and because she's got a more pathologising idea of what mental illness is it was like 'Well I'm reducing my medication', and she was like ' So are you feeling a bit manic'! And I just thought, you know, I thought, are you just trying to rain on my parade! I mean really hang on a minute I'm happy! It's a positive thing, No I'm not feeling manic, thank you very much. I didn't say that, I was just like – I just kind of wandered off like a sunk balloon you know! But it's like that's when I feel disabled by the outside view of me.

And as one conversation highlighted:

> I think the other question is, um, your disability, if you're amongst other people who've got the same kind of illness, then you feel normal. But then you don't think that you've got lots of problems. But it's when you come out of it – of the comfort zone – and trying to be in the system, you know,...and you've got to fit, to do this deadline or whatever, then you realise that you have got a disability. But when you're in that group and you're meeting them regularly, then you feel like you haven't got an illness and you can you know do things and do other things. Everything is in a different way and different structure, so the ability and disability is different in different environments.

> Why would you feel disabled if you weren't able to keep up with the stressful nature of modern life?

Because modern life is a lot of structures. At the moment I can't really follow structures. I can only do one thing at a time at the moment. So if there was like, say, I was working in an office nine to five, I don't think I could do that. My concentration loses things and if I lose things, then I get penalised…in a work environment, kind of thing, I'd be forgetting things and I don't think people would like to employ me if I'm losing and forgetting things and stuff like that.

And similarly, in another discussion, service users said:

…it's a social understanding of disability…You know what's happening to you is not because you have a chemical imbalance, it's because of all this crap is coming to you. For instance you know these are the socially constructed experiences that have brought you to feel distressed.

You've been disabled by the trauma.

Your ability to be yourself, actually your right to be yourself has been made impossible because of things that have been constructed around you or that you found when you were born and you try to grow up and find that nothing fitted. So you're self is disabled by those things.

Some participants felt that medication supported them in maintaining their well-being and that without it, they would be disabled.

I've just identified one of the problems…is that I'm on that bi-polar spectrum, as well and I'm on a period of stabilisation medication. And of course I'm sat here thinking, well I don't feel disabled at the moment but actually it's the result of the medication…it just hit me really strongly when you said it then…and I think that's one of the real risks with mental health isn't it, that very often people get through situations where their medication keeps them stable and they feel like it's solved everything. And we know that a number of people actually stop taking their medication or reduce their medication or do without [it] and become ill

again. And I just found myself exactly in that position as I was talking then, I found that quite shocking actually…

And it's the same with diabetes or something isn't it, if you didn't have the medication, it's important and every so often things happen to people and you couldn't live a full life [without the medication], but you can live a full life, but you're still disabled.

But it's like any physical illness, you know it goes into remission or you get better and then it flares up.

For others being asked about the social model of disability led them to thoughts about their identity, and identifying as disabled as a means of getting some support. This could be beneficial or it could be negative and reinforce stigma.

Disabled is something that you tend to use if you want some benefits for something.

Yes.

I see myself as suffering emotionally and sometimes I suffer physically, but I think I should get the payments that I'm entitled to, and the DLA (Disability Living Allowance), but I don't think I should need a psychiatric drug.

The disability label is a passport to rights and policies, which can substantially improve people's lives. However no one, not even physically disabled people, wants to identify themselves with it, even if they use it as a passport.

I mean the other thing because I mean I have severe hearing problems…I mean if I say I've got impaired hearing and ask for special treatment – for people to talk louder or whatever. So if I'm in a situation, you know I fill in a form for a meeting or something and you say do you have any special needs – Yes I want to have, I want to be able to sit where I can hear best. I want to be able to tell people to speak louder or more clearly or something, so I don't think there's any…for me that's an opportunity.

Difficulties with the social model

As with the first stage study, some service users/survivors did not understand what the social model of disability meant and were confused by the question and definition we offered. Not everyone joined in to discuss this question in the focus groups we held. Discussion was sometimes limited – as this participant highlighted – even though (s)he related to being disabled:

> Don't really understand it. Yet again I don't understand the question. I think that this survey is very badly framed and is confusing the hell out of me...In short however, I do identify myself as a disabled person and strongly believe that mental health service users and survivors are stronger when banding together with the broader disabled people's movements.

Despite our efforts to explain the social model clearly, it was confusing for some people.

> I'm just trying to get my head around what the question was.

> It comes back to language again!

> (Laughter)

> I was going to say exactly the same!

> Could that be broken into clear English! It's too long! (Laughter)

Some people stressed that clearer language needed to be used if everyone was to understand the meaning of disability.

> I think that more could be done to explain what 'disabled' means in a mental health context. I think [your] definition is clear and coherent but I'm not convinced that all other people share the same understanding of the term.

> I think yeah, I think it would be useful to go under the banner of the social model of disability. I think it's just being clear by what we

mean by that and I think that the more I kind of hear about people's experience who've got physical health complaints with medics it sounds quite similar to the experiences, you know the bad experience that I've had and other people I know have had with mental health problems. So there's some similarities. You know I think that we've just got to learn to be clearer in terms of how we define it, the model, a bit more in terms of what we think disables people in society. What does society do that contributes to disabling people.

Some participants felt that people should not be tied to any one model, although they could see the social model of disability as being helpful in some ways. They also had their own ideas for different ways of thinking. For example:

> Don't really understand it. I do not understood what you are asking me...I have no problem identifying myself as a mentally impaired person. In my case, this is a functional impairment...as with the model of impairment and disability set out by Vic Finkelstein in 1975. Social responses to this defect in my character can either enable me or disable me. Beyond that, I would not apply a social model of disability to mental health but would work towards developing a social model of mental distress, building on the work that survivors have already done on this in the past. I think we should pay more attention to the way that society enables us (as well as disables). If we did that we would be in a better position to defend the enabling facilities when they are under threat – as many are now. Day Centres and other community facilities are an obvious example.

> I think it should be up to the individual as [to] what group they are included in, and that they should have the choice.

> Yeah, definitely. But what we need though – from my personal experience, and from a lot of the reading that I have done – is that a huge

proportion of the people in touch with mental health services have experienced trauma...even if they haven't experienced trauma before they enter it, they may go on to experience trauma through sectioning and coercive practices. So I think for us we really need to think about incorporating the trauma model into a social model. I think that's really vital for us and that is different, I think. That's an important point of difference. And that may be why our language, well for me – everyone has different views, don't they, but that's one way in which I think our language differs because of the relevance of trauma.

The issue of impairment

As was the case in the first stage of the project, many people were clear that while they could identify in some ways as being disabled, by society or medication, they did not feel they had an impairment. Impairment emerged again as a problematic issue for many mental health service users/survivors. Many do not see their distress as a fixed or permanent state. As some stated, at some points in their life, people may feel or identify as disabled, but this can change from week to week, to month to year.

> Broadly not in favour of this [association with impairment]. The problem for me is that it treats our difficulties with thoughts, feelings and behaviour as fixed and permanent, which, in some instances for example. 'personality disorder', makes it similar to the medical model. Also, with certain physical impairments there are specific actions which can be taken to overcome barriers, for example, hearing loops, ramps. I'm not sure what the equivalents are in mental health.

> The impairment issue is difficult. Maybe if we use a concept like 'condition' or 'state' with the built-in understanding this fluctuates, is not static but responses to the social environment. The episodic nature is important to factor in too.

I mean it does vary doesn't it, one's own perception...So I mean mental health it's up and down you know, hopefully you're not going to be suffering with mental health, ill health, all your life. I don't think I've ever and none of my friends have actually said that I'm disabled to me. So it doesn't quite fit in.

For some service users/survivors, part of the problem, as with the social model of disability more generally, seemed to be their reluctance to be tied to any one system of thought. Perhaps this reflects the damaging effects they associate with being seen through a monolithic and overpowering medical model.

> But I think it varies. I mean it's up to each individual what they call themselves, I mean sometimes I think of myself as disabled, other times I won't and that will change from week to week or day to day, or who I'm talking to.

At the same time, this second stage of our project highlights yet again how problematic the specific concept of impairment is for many mental health service users. This was expressed in various ways in numerous comments.

> I think I agree that it's incredibly helpful to think in terms of a disabling society, very much. It's obviously very powerful for a wheelchair user, for example, to talk about physical barriers, but it's also I think very powerful for mental health service users to talk about disabling society, and the way in which, for example, families and the workplace may, um, be disabling in the way that they are set up and the expectations that they have on people and so on. So I think that's really helpful. But I also agree that the language doesn't sit comfortably. So impairment doesn't sit comfortably and disability doesn't sit comfortably. And I don't know what you can do about that...So yes, so I think, yes it's great but the language doesn't translate across and we need to think about that carefully – because we don't want to lose people, those

people who feel, for example, I wouldn't, I wouldn't accept that I have an impairment or a disability, because I feel that my problems are caused by childhood…and a dysfunctional family. That doesn't mean that I am now disabled, I think that's a nonsense for me, it makes no sense. But it does mean that I have mental health needs and that I can't engage in the work place in the way that other people can for various reasons. So I think it, er, society can be disabling where there are no…where the employer doesn't understand my limitations, but I can't accept that language.

…But I don't see it as an impairment, I see it as an affliction, an imposition put on you where things have become unbearable and something's given, something snaps. You can take so much and then it just goes. And that's could happened to anybody it could happen to the Queen as well.

I can see problems in terms of – you know – applying the social model of disability to mental health and mental health service users in a kind of pure way as it was developed originally, you know, for people – disabled people, people with disabilities. I mean all these are not easy answers and you know I guess I've got more questions and sort of ambivalence rather than answers. I mean for example, I don't consider myself as disabled, although I used to be on DLA – disability living allowance, and when my mental health crisis was acute that was very disabling, but I don't consider myself as disabled, or I don't think that I've got an impairment. I don't have a chemical imbalance in my brain that makes me depressed, I wasn't born with it. So, um, I think I can see why it would be problematic and it is problematic to try and apply in a kind of sort of purist way the social model of disability to mental health service users…so I guess it's more complex and more complicated…

We are disabled in that we are discriminated against in the wider society. But we are different to other disabled people in that we don't have an impairment.

I think we have to make some distinctions here, as there is a clear difference between physical and mental ill health. The idea of utilising a term such as impairment does not sit well with me. Is there a difference between this and the medicalised notion of ill health? Taking aspects of this model would be useful, i.e. the overwhelming use of medical model within psychiatry impairs us.

Building closer links with disabled people

When we are asked participants whether they thought that the social model of disability and developing closer links with disabled people could strengthen mental health service users as group, they mostly responded by concentrating on the 'closer links with disabled people' part of the question, ignoring the social model of disability. Many service users/survivors felt that working collectively with disabled people was positive and that they could learn from each other and support one another:

I would tick a box as being disabled, I am onside with that one. I'm onside with going out and standing next to people in a wheelchair and campaigning about and objecting to things like the bedroom tax, yeah absolutely.

Yes, definitely, I think it helps other people to understand what having a background of mental health and difficulty actually means, and that it can help them to make like reasonable adjustments. And closer links with disabled people will I think put us in a stronger position in terms of relating to people that want to understand more about a mental health problems.

Many participants thought that it would be in mental health service users'/survivors' best interests to join with disabled people, particularly from a 'rights' based approach.

> I do think we should be joining. I think there are areas to do with human rights – definitely rights based approaches. And I think in many ways mental health [service users] haven't got as many rights sometimes as people with other disabilities, so I think it would help mental health to join with [the disabled people's] movement. I strongly agree, because so far all social justice work (which is a crucial part of the social model) has been undertaken by physical disability activists. Mental health has been riding on its coat tails. I do identify as disabled.

Some service users/survivors stressed that together they and disabled people would be stronger.

> We need to fight all our corners together and not be divided by diagnosis. Strength in Unity! Many people have dual-diagnosis anyway.

> It stands to reason that a group are more likely to be heard than one voice alone.

> …I do believe in people working together as a social unit, and so, you know, to me, you are always going to be stronger. There are always going to be problems in working together as a group, the bigger the group, the bigger the problems probably, but you are still stronger. And we are as a minority, two minorities, well several minorities, in a society that doesn't have a high opinion of us and it would definitely be a benefit, I would have no doubt whatsoever.

Some service users/survivors felt that working with disabled people could also help them recognise common concerns which would have a unifying effect.

> I agree and in the work I've done about 20 years ago with disabled people, it changed my whole perception. Myself…I had a breakdown, but I didn't see myself as having mental health

problems at that point, but I knew that something about that experience was very much in common with people with physical disabilities. And yeah, it was truly interesting to think about common issues and common ground.

> …I think you can only learn from creating alliances with people, I don't think we should separate up and say, well we're different from you and we're different from you…You know, you don't have everything in common but you have some things…And I think I mean you've got to have somewhere where is safe enough to acknowledge and accept those differences, rather than to say let's all agree on such and such.

> I think the mental health service user movement can learn a lot from other disabled groups. Many other groups are ahead of us in many respects. The NSUN [National Survivor User Network] work around involvement I was involved in showed that many of the concerns around involvement for people with drug and alcohol dependency were similar to those faced by mental health service users.

On the other hand, some mental health service users/survivors thought that it was important for them to keep their identity as a separate group. While they could see some similarities, they felt either that mental health service users could lose something from becoming too closely identified with disabled people, or that the two groups were fighting for different agendas:

> Yeah, I mean there is a difference between disabled people and mental health service users, I mean we don't have everything in common with people who have essentially a physically disability…We both need to carry on in our separate ways, but we can still work together. And the same applies to learning difficulties.

> I think I agree there are common grounds, but I think we possibly have more common grounds

with people with intellectual disabilities. Because um, people with physical disabilities, or rather the other way round, people with psycho-social disabilities, or people with intellectual disabilities are still the only group in society who can be forced to receive treatment by law.

Every group's experiences are different and sometimes by being in a huge group all together, things that were swept under the carpet by society gets swept under the carpet in the group, and then it loses its potency. So I think you need both. I think you need the links and the independence.

There were, however, some service users/survivor who thought it was possible both to be part of a larger disabled people's movement and retain their own independent identity.

Strategic essentialism is still important sometimes – but there is room for everyone and diverse positions in a movement.

I think that the social model and closer links widen the opportunities for mental health service users to engage in collective action. I don't think it's necessary to view this issue in terms of 'a disabled people's collective' or 'a mental health service users collective'. I think it is likely to be appropriate to voice some collective concerns as part of a wider disability group and others as a group of mental health system survivors.

Whether their fears were justified or not, some service users/survivors were worried that working with disabled people could just expose them to the same prejudices as operated in wider society.

The analogy is where black people, when Asian people, when they got kicked out of Uganda all of a sudden their brothers and sisters were up in arms…and then when they got their foot in the door to take positions of power in the councils and stuff like that, all of the sudden they shunned the idea of being black and they were Asian once more, and they weren't black

anymore. So that has [been] a bit of bad experience for us black people. And also as I was saying with the Gay Pride as well they hooked onto our one month in October that we claimed as our own for black people… they've linked with that with their Gay Pride but they are still as racist as anybody…So I don't know if it is a good thing quite frankly, a good thing or whatever. I think all black people have had to always fight being the bottom of society and bottom of the rank, and when we won a victory other people have benefited. So I don't know if it is…yeah numbers in a collective group, but not always principles are shared the same.

I mean why has it not happened…people with physical disabilities – there have been groups and associations of them for so long, why is this just coming from us. And historically it's come from us…I mean I think for instance and I'm not just thinking the UK, in France the physical disability movement they've got their own funds, there's loads of money around what they do, what they organise for their community. They've never, ever you know come across to us. It's always been the other way round, it's the same with here.

But they['ve] got the same level of ignorance [as non-disabled people] because as they are part, as far as the mental issues concerned, they're thought of as part of normality and people are very reluctant to look outside their own reality. So we can't accept them to want to link with us and in a way anymore than we can so called normal people because they perceive themselves as 'normal people with a broken foot'.

Unsure…I think that people within [the] mental health [system] can have views on other people's diagnoses or care they receive, for example, someone with bipolar said she couldn't see why I had a CPN [community psychiatric nurse] when I only had BPD [borderline personality disorder]. I would worry that rather than bringing people together, pan-disability there may be a sense that one type of impairment is 'worse' than another.

EXPLORING THE IDEA AND POLICY OF RECOVERY

Since we undertook the first stage of this project, the idea of 'recovery' has become even more important in the field of mental health and has come to be seen as a guiding principle for UK mental health policy and practice. Although we referred to the emergence of this development in our earlier report, it was not something we discussed with participants in the project. However, because of the greatly increased policy importance of the idea, this time we thought it would be helpful to see what service users/survivors feel about it.

We found that participants had very mixed views on whether recovery is working out to be helpful for mental health service users/survivors. Most felt that the idea of recovery could be helpful,but that the policy as *implemented* was not. There were strong feelings that the idea of recovery, which was supposed to be user-led, had been hijacked by a government policy of 'recovery' which was narrowly defined and was unhelpfully framed in terms of a government agenda. The central aims of this agenda were seen as saving money and cutting services, rather than supporting service users to deal with their difficulties and improve their situation. Again, issues of language and meaning figured large in the discussions that took place and people's responses in individual interviews.

Some service users/survivors did not find the idea of 'recovery' a helpful one. They challenged its assumptions and fit with their feelings or experience.

Happiness is not a goal, it's a process, well journey isn't it. It's more like a zig zag!

Yeah, I mean it can be up and down or whatever. It can look to other people like, you haven't got anywhere, but actually if you're feeling differently about things, then that's good really.

I can well relate to the idea of *well-being* – that's what we're all aiming for in life I suppose. Recovery suggests to me that I've got to turn into something different, not be myself. Could it be that I learnt to live with myself with all the ups and downs and difficulties and manage them, learn particular ways of coping so to achieve wellbeing.

I think concepts such as stability and functionality might be more helpful. By focusing on recovery one excludes those who will never recover from support. I was discharged from mental health services many years ago because, to quote my psychiatrist, 'There's nothing more we can do for you now'. Whilst that may have been true in the sense

that they couldn't 'fix' me, aka stop me fitting or hallucinating. They could still have offered some long-term support. The focus on recovery encourages crisis management rather than prevention.

On the other hand, a number of service users/survivors valued the concept of recovery. They felt it could make a real difference in improving the lives of service users.

I think the recovery model is a good model. I mean I mentioned earlier about the fact that I've got some best friends who have been stuck in the mental health service all their lives, you know, and they were made to feel dependent and controlled, so I think it is a good move forward really. The only anxiety I've got about it is that people are being discharged from services before they're ready to be discharged from services. And that can lead to anxiety and stress. But um I do believe in the recovery model, yes. I don't think it's just about a way of saving money, you know I think it does make sense really.

This could vary considerably with each individual. As a concept it is the way forward. Many existing [service users] feel dumped and neglected. Recognising that [mental health] problems do not signify [an] end of normal life was meant to have been implemented prior to the closing of the asylums.

A policy which does not consign [mental health] services users to a dependent half life for the rest of their lives has got to be good. The policy will be more effective with people new to services using 'early Intervention' rather than people who have been institutionalised in the system for many years.

I think this sort of emphasis of recovery, is perhaps something that people do think about as an alternative. As I said although they may not see recovery approaches when they go into hospital I think, you know, the whole thing and the whole fuss around recovery it perhaps is, you know, a way to perhaps help to make people

think in different ways as well as the medical model.

Other participants had ideas to offer about how a recovery model could really work in practice. Many talked about receiving the right support to achieve their idea of recovery.

I think it needs to be done properly. There needs to be people on hand who can really do some intense work with them and help them to recover. It doesn't just happen on its own.

I think it works when there's an actual support worker working with the person. Yeah, you know, you can't just leave someone to recover and it just happens. You know, there needs to be some intense work that happens with that person to enable them to recover. Like a support worker actually taking them to a voluntary position and actually staying with them and doing stuff with them, not just leaving them, and you know, asking them to just sort themselves out, that sort of thing.

Some service users/survivors emphasised that better support would require joined-up working between services to ensure that each person got the long term and consistent help that they needed. Services had to be flexible to match each person's different needs but common rights.

I think...recovery will, from my point of view, only work if the person...has been shown what their rights are – and also the recovery model is used throughout the whole system. It isn't broken down. It starts from the psychiatrist to your CPN [community psychiatric nurse] to you day centre to your GP [general practitioner]. So it shows a whole image of how you are recovering...

As one conversation in a group discussion highlighted, this could be very different to people's usual experience:

...I'm a volunteer...and often I come across patients that feel very anxious about their discharge because nobody is talking to them.

They've been on the ward three months. Nobody's had a conversation with them about anything that's going to happen...

It's like being abandoned, isn't, like being abandoned...

And sometimes I think...why don't they start it as soon as possible?

It's like prison isn't it.

...And get them out and about and you know you see what I mean, just helping them get out and about as soon as possible.

I agree.

I agree entirely with what you say. I think actually you should start planning for your discharge to recovery as soon as you're fit to.

Yeah.

Many participants, however, thought that the policy of recovery is not working. They thought it all depended on who defines recovery. If it is not defined by the service user, then it would not be empowering or positive, as they would not have ownership of what happened to them.

It depends on whose definition you're working to. If recovery is getting back to work then, no, if recovery is defined as having a life then, yes. To be put quite simply.

I mean I've been in programmes where the focus is around recovery...but it isn't recovery defined by me, it's recovery defined by them. And it quite often doesn't work for me what they want me to do, but they're not listening. They think they know what recovery would be, but it isn't for me really.

I think that for me the idea and policy of recovery sounds ghastly. Having the possibility of recovery or having ideas about recovery is very different from having the policy of recovery in quotes.

Depends who defines recovery! It must NOT be defined by going back to work!

Most service users/survivors who took part in the project felt that the idea of recovery has been subverted by Government policy. It was defined in terms of people coming off benefits and getting a job, rather than aiming for improvement in their lives and life chances. Thus, it had been co-opted to become part of government 'welfare reform' policy. This was happening as the same time as public services were being cut as part of 'austerity' policy and this was having detrimental effects on service users.

Recovery's been hijacked and transformed into something else, it's not what it was meant to be and people are misquoted...'Recovery' is what you need it to be for you, you know, to go to the point where you want it to be. Whereas recovery's come to mean put you back to where you were, tax payer whatever, so yeah the fact that's its again been hijacked and twisted by health professionals um the powers that be, policy makers...

...I think there's some concepts in mental health like peer support and recovery which originate from service users, and they have been really important. Recovery has been a really important concept, because I remember ten years ago going to a conference and a professor standing up and saying, um, "one of the worst things for a service user on receiving a diagnosis is learning that they will never work again". So I guess we do forget that ten years ago there was a belief that once you had a diagnosis it was game over, you were going to have life on benefits, you were never going to be able to work in the workplace. So we do not need to do justice to the achievement which has been to show that with the right support we can lead the lives that we want to. So that's been fantastic, but it has been co-opted, it has been bastardised, it's removed the concept as it's now implemented in is removed from how it was originally generated by service users, which I guess is to be accepted because it's interpreted now within the fairly narrow medical framework quite often with the odd nod to service user goals.

...there's an emphasis on sort of individual efforts to recover. So you are responsible for your recovery and you know and you have to take control of your recovery, which in principle is a very empowering sort of idea to take control of your life and to be responsible for your life, but I think we see that sort of translated often into cutting services. So you know, so ok you are responsible to recover and it's down to you to make the effort...and sometimes it can, you know, it can be used as a sort of justification for cutting services. So that's not at all helpful...It seems that people are told how to recover and unless they are recovering in this way they, you know, they're not considered as recovered. So for example, you know, in order to recover you have to be back at work, and some people can't be at work and for some people work is detrimental to their mental health. So, you know there are all these issues in the way that, you know, the recovery model is sort of used that are quite unhelpful actually. Although the idea of recovery and the principles are, I guess very important.

Some service users expressed their concern that the responsibility for 'recovery' was increasingly placed on the individual service user. Then they could be blamed for not 'recovering'.

What is a concern, is the way that the concept has been adopted and morphed into something very different than was originally envisaged, by politicians and health and social care providers. A narrow understanding has become at times a convenient excuse to use individual agency as the reason why an individual fails to 'recover'.

I don't like the idea of something that I see as a sort of recovery agenda. I mean people are so different...You know if you define it too much you make people feel like they're failures...I'd be careful around a policy of recovery, I think it would be better to have a more open approach towards the meaning of recovery and let the person concerned define what they see recovery as. Because for some person it will be being able to stay up all day you know without being in a lot of pain.

In some ways it's helpful – but I've known it to be very harmful. I've known it to be used i.e. misused, by professionals to deny service users the support they need by saying 'You're recovered so you no longer need such and such'. I've also known service users to be pressured into taking a step they are not ready for because their service provider wants to 'prove' they're recovered in order to get funding. I know someone who was pressured to say she was at a higher point in her 'Recovery Star' and told that if she did not soon show signs of recovery she would have to leave the service. I think there needs to be a 'Reclaim Recovery' campaign to take back the recovery concept from professionals who have hi-jacked it!

it has its place, but currently dominates mental health services which contradicts recovery principles and focus.

Service users/survivors talked about services supposedly dedicated to 'recovery' that had changed in name only and the difficult and damaging results this could have for them.

[Recovery] was 'invented' by the user movement and has been hi-jacked and corrupted by services. I've been onto 'recovery' wards in hospitals where all that has happened is that they have been repainted, and new carpet laid, and no staff training or cultural change has happened in terms of how people are helped to 'recover' in that environment. It's still too closely associated with a medical recovery understanding because of the confusion caused by professional takeover.

...and also there's this thing of. I think it's quite commonly known, that teams will rename themselves 'recovery teams' with no other change in their practice, no shift in their philosophy, no shift towards a social model, they just rename their teams.

…It is used as a way of pushing people out of secondary services and pretending they are doing us a favour. Everything is rebranded recovery orientated and this seems disingenuous. Something like being able to have one to one time on an acute ward is relabelled a recovery clinic…People are discharged en masse from secondary care and there is little success if you want to be re-referred if you get unwell again. Access teams can choose who to take on. You are starting from scratch with new staff who don't know you – if you are 'lucky' enough to get an assessment. People have no choice as to whether they enter a recovery pathway. Everything is about this 'recovery' trajectory with little understanding of all of the problems that are still out there for someone leaving services e.g. getting enough income, obtaining medical evidence for benefits, finding a job and managing to keep it, decent housing etc.. The recovery ideal could work against someone's claim for benefits as the DWP doesn't 'do' recovery but makes awards only to those in greatest need…I worry services are becoming eroded, but that this is legitimised by saying in the past we got things wrong and you shouldn't have remained in services like you did – this promoted dependency. When I hear that, or it's hinted, I just feel a time waster and that I was to blame for being under the CMHT [community mental health team] for over ten years. I feel like I got it wrong. This then undoes my 'recovery'.

VIEWS ON SOCIAL APPROACHES TO MENTAL HEALTH

In the first stage of our project we found that service users saw social approaches to mental health as much more helpful than prevailing medicalised ones. They felt that broader issues needed to be taken more into account to counter the individualisation of mental health issues.

Our findings in the second stage project were very much the same, but they also dug much deeper. Most people who took part felt that social approaches to mental health were the most helpful. Some felt that such social approaches needed to be incorporated more widely within medical practice. There was a feeling that social approaches were needed to take into account the whole person.

My own opinion is that it is naive at best to not consider the influence of the wider societal issues in understanding individuals' experiences and the reaction that this provokes. Services, treatments, need to be situated in a social context, and not focussed on some supposed pathology of the individual.

Yeah, I realise how different my life would have been had I of just gone along with medication and just with the medical model and I wasn't, like other people. I wasn't given any choice whatsoever on anything. But because I happened to be have studied psychology at university, before I fell ill, and I had seen mental ill health in the family, stuff like that, I knew that everything that was happening to me was circumstances and if I wasn't in those circumstances, I might, you know, it wasn't necessarily genetic. I proactively sought for social help and eased myself off medication myself and I've been

well for years and years and years – but that's because of the social approaches that I've used.

I am hoping we are including alcohol dependence in this survey?...Alcohol distress is usually (over 90% of time) caused by social factors as opposed to psychological ones.

The whole approach needs to be person-centred again...you know the background is important.

Whilst most people felt that social approaches needed to be given more priority, some participants also felt that a combined or holistic approach which highlighted both the personal and the social, the psychological and the sociological, was important. They also articulated the relations and overlaps between they saw between medical and social understandings.

Well, I think the answer has to be a combined approach. I mean, I am very aware that if I stop taking my medication, then I will get unwell. But there is obviously more to good mental health than someone simply taking medication and a social approach can provide the help and support as much needed and people to flourish in society whatever their background.

It is about looking at both because when you are in an acute crisis there is a place for that medical model to help with that crisis situation. The rebuilding it takes you on that journey into the social model and looking at the barriers you are going to face and following your recovery. And so I don't think it's an either-or, it's part of a continuum.

I think one of the things that really confuses me is that I'm not entirely sure that there's a concrete wall between the medical model and the social model...It's not always that clearly defined and it might be continuous. And certainly when I became acutely ill, the medical model at that point was valid and useful. But I think once the transition from being treated as having a problem to how can we assist you to re-engage with the community, I think that's where the problem was: the transition between the two. And I think it's because it's often seen as they're two separate elements where actually it's a continuum.

I don't think it's an either-or. There are physical illnesses we might not get if we lived differently, or if society were different, but we still go for treatment when we do get them. The same applies to some mental health conditions. I believe that medical research will eventually find out a lot more about how the brain works and what can be done to help people with brain injury, developmental problems, and psychotic illnesses. But although this can alleviate suffering, it will never be the whole answer. I think we need to start TALKING and THINKING about mental health in a different way, so that the medical approach becomes just one PART of the response to people in mental distress. Meanwhile we have to put ourselves forward to research and practice the social models and show that they work!

I think it is very unhelpful to set up a duality between either it being the medical model or a model of providing recovery oriented and psychosocial support – personally I think both are often needed at different times and for different reasons. I agree that mental health services are too focused on acute problems and symptoms and do not address the on-going support needs of many people – and nor do they help people enough to understand what is going on for them and work out how they might best manage themselves and their lives in ways that are most satisfying. Polarising medical treatments and the recovery model just creates more confusion for people who are seeking help for their problems – and can be understood as competing discourses which simply add stress to an already difficult situation.

This second stage of the project brought out more of the complexity of people's thinking on models of mental health. Some comments highlighted people's reluctance to impose another single monolithic interpretations of their experience on service users/survivors. So while valuing social models over medical models, they didn't want to impose crude new exclusions.

...I do not think that one approach will work for everyone. People are different and there needs to be a range of different approaches so that people can find something that works for them. Some people want to stay away from other mental health service users, not speak about their problems – such strategies should not be criticised. Some people do not want to talk about the past and what has happened to them because this is too difficult and traumatising and focus more on current life and practical issues and these strategies should not be criticised. Some people want to talk about what has happened to them and make sense of what has gone on in their lives, and therapeutic approaches are useful for them (I have been in therapy for years and see it as a core support mechanism), but such supports are not everyone's cup of tea. I think that any model which claims to be the 'right' way of doing something is potentially problematic, because no one approach is right for everyone.

...I say again, a COMBINATION model i.e. a holistic approach is important. In some circles, a challenge to the predominant anti-psychiatry anti- medication model would also be helpful! I say this because I've seen this model (i.e. anti-medication/psychiatry) to be as repressive and oppressive as the reductionist exclusively medical model! THE IMPORTANT THING IS THAT SERVICE USERS/SURVIVORS ARE ALLOWED CHOICE...

Some people drew a distinction between the medical model and the use of medication. They could see medical interventions having a part to play, but not the medical model.

I would say that this is not an either-or. There is a place for medicine – that has its place... The idea that you can also take medication to deal with symptoms and to get you on track – because I've also had a very good experience when I first took anti-depressants...I had a psychiatrist who was very wise...I had a very good experience and I recovered. I stopped taking tranquilisers within a few weeks, I stopped the medication for 10 months and I was well. So I have both kinds of experiences. We should accept medical interventions, but not the medical model, if that makes sense.

But I want to, to sort of point out that sometimes people seem to...equate the medical model to the use of medication or the use of or taking psychiatric drugs...I mean I don't support the medical model but I do take medication. And again I have a very ambivalent relationship with medication, because I mean – or kind of love and hate kind of relationship – because I know how damaging the side effects...you know [can be], I've put on so much weight from several types of anti-psychotics and all that. On the other hand, there has been some association between taking medication and getting better...the medical model I think is not just about taking or not taking medication and I think that is important...to point out.

Service users/survivors also raised practical problems in relation to implementing social approaches, in terms of who will take responsibility and the costs involved. There was some concern that 'social approaches' might be hi-jacked by services and their meaning changed in the process. This might mean that people were discharged from support services before they were actually ready, or support was left to the 'community' as a means of cost saving.

But the trouble is that same old problem, people get hold of these words...there's something called social inclusion. You know there's a mental health commissioner in Bristol, she's very proud of herself for closing down day centres that are for people who have mental distress because she says well they need to go to Starbucks and mix with the rest of the community. So they use this social inclusion policy to take away the very services.

Social approaches may turn into recovery and services light. It may be that we are pushed back to work too soon and not given time out of life if we need that...Services may pull out further saying it's society's role to treat these people rather than the health services.

The benefits of social approaches

In our first stage project, service users/survivors highlighted that social approaches to distress would be helpful because they took into account the wider issues like barriers, stigma and discrimination experienced by mental health service users, instead of focussing narrowly on what was 'wrong' with the individual. The findings from this project add further weight to this conclusion. Most people who took part felt that social approaches were more helpful because they addressed other key issues affecting people.

Treatment to help you build your life again includes tackling issues that hold you back. The difficulty is most don't get the appropriate

therapy to help build confidence and reclaim a life away from an illness even if someone still needs meds to keep stable. Professionals have a duty to understand barriers and what holds people back such as inadequate housing, poverty, social deprivation, etc...

It's also important to take into account difficult or abusive family backgrounds, ethnic and cultural differences, problems with benefits and social housing, physical ill health, etc. All of these things can both trigger a mental health issue and cause it to be misunderstood and mismanaged.

I think that the experience of barriers, stigma and discrimination can have a direct detrimental effect on an individual's sense of wellbeing. I also think it is meaningless to conceive of an individual without an awareness of their social circumstances and relationships with other people.

Participants discussed areas in their lives where social approaches had been beneficial in supporting their and other people's mental well-being:

I'd agree with [a social approach]. For example, when I got involved with the social inclusion programme with the trust, and I was assigned a support worker as such all I can say it that it has had a major, major positive impact on my mental health, you know, like in terms of if it weren't for that, then I'd just have to rely on medication. I would not probably be here today, you know, so I think social approaches well to me I think they're positive...I like the way it takes a holistic approach to you as well and talks about things like your race, your gender and say what might have caused the illness. And I think mostly to me, from what I can gather, most people's illness is usually caused by some trauma or something that's gone on in life, you know. And that's not what's being addressed in reality. And talking therapies...I'd put it above going to see a psychiatrist, because to me a psychiatrist is not a be all and end all – far from it. I'd rather see a psychologist, you know.

...well I mean there's some therapies aren't there...that have been going for a long time. Like art therapy that says, you know, you have to look at the whole environment of the person, you can't just look at the symptoms... I think about the best experience I've had with a therapist was the fact that she saw me as a whole person and she looked at me in terms of not just my mental health problems, but my home context, my race, you know, my age, all those factors – the fact that I'm a mum. So she kind of looked at all that and kind of explored how...helped me to explore how – I made sense of things, or didn't make sense of things sometimes and help me to unpick it. So yeah, I think that's really helpful.

I had a good upbringing and a pleasant social environment, so you could say I got no reason to be depressed and develop depression. But... there were events in my life I couldn't control, gave rise to emotions I couldn't deal with. And so the isolation of being in a good environment and being unable to turn to anybody and having a lot of bereavement on top of it, it all sort of piled in on me. So yes, social environment certainly. But more so the person and the factors in their particular life certainly have a great bearing on it.

Social approaches were felt to be very important for people from black and minority ethnic (BME) communities. They were much more likely to take into account issues of culture, racism and migration.

I think particularly if I look at the experience in my own family, and the experience of other people I know who are from, say African Caribbean backgrounds, and whose parents came here as immigrants...it's definitely I think not talking and being aware of like the impact of like racism and stuff. ...it's kind of like you normalise so much, as growing up in this country when I was little you really normalise racism, you don't kind of realise the impact that

it really has on you. And then it's only as you get a bit older that you hope and you kind of start exploring things and you think 'Well no, people shouldn't be able to treat me in that way' you know…It's two things, there's such a kind of repression of that I think in communities, in minority communities. And then I think there's such a dismissal of that in the wider white community, you know, that it's not really taken on board and examined in terms of how that really impacts your life and how your mental health is, you know. So for me I think it was really empowering that I had a therapist, she wasn't black, she was a white women, who was willing to explore that with me and explore her own feelings around that. And you know that to me was really, really empowering. You know I think it was the first time, really in my whole life, that I really began to really look at the effect of certain things on me.

I think, I mean, anybody who tries to dismiss racism and tries to separate it from the mental health…they're in cuckoo land to kind of speak…racism has got [to be], you know, the consequence of that would be mental illness, at least depression and so forth. And you know some people will say 'Oh well there isn't racism anymore…it doesn't happen anymore'. Well what are you talking about?…Racism and things like that, does have a major impact I think on BME communities.

…social approaches would take into account the sort of social determinacy…the social approaches would consider issues of intersectionality…like the mental health service user identity stuff doesn't exist in a vacuum. So you know, a lot of mental health service users are also, you know, from sort of, um, BME backgrounds…so there are other sorts of, you know, factors to do with oppression and discrimination. So it's important to look at these factors as well in combination with the, sort of, mental ill health. And I think yes social approaches have the potential to do that.

Opening up the discussion on social approaches

Most service users who took part in the project felt that more discussions of social approaches in mental health and more challenges of existing medical approaches would be helpful. This strongly reinforced the finding from the first stage project. Participants then highlighted the importance of developing discussion, particularly among mental health service users and their organisations, about social approaches to mental health issues, policy and practice, as a basis for improving the life chances of mental health service users. This view is still strongly held by a wide range of mental health service users.

> Yeah…I imagine through, you know, more wider and open discussions about these things and, you know, not allowing the over-reliance on the sort of medical approaches to dominate.

> Yeah. I definitely think there should be more discussion.

> Absolutely. This is the only way a fuller understanding of mental health, along with a less discriminatory society, will ever be achieved.

Some service users thought that such discussions and challenges are already underway.

> I think these discussions do happen now far more than previously. In my recent episodes, for example the Trust now has employment support and lots was done to try to help me maintain my job and get me back asap. By contrast, in the past it was more about keeping me away from stress and work…I do believe the move and change is happening far more and cannot be avoided.

> Compared with when I was in the mental health system – mainly in the 1970s – there is a lot more discussion and challenge. I would like to see the major mental health charities do more in this respect. I think the argument has been won but money and power keep the medical model in place and ever expanding its reach.

MOVING FORWARD WITH SOCIAL APPROACHES

A key aim of this second stage project was to take forward more social approaches to mental health issues – if, as has been the case, this continued to emerge as a major concern of mental health service users/survivors. Service users taking part in this project had many ideas about how this could be done. These started with an interest in how greater openness and receptivity towards social approaches to mental health could be built into areas such as professional training, education, practice, policy and research, as well as the media.

While most participants, as we have seen, felt that a medical model still predominates, there were some who felt that a change, or at least the start of a change was taking place in the way that some professionals worked with and supported people with mental health issues. Participants talked about such a challenge within professional practice and more awareness of alternatives to medical approaches. Some service users thought that some professionals were becoming more open to social approaches and are critical of the medical model, although most people felt that this was more at allied health professions, general practice or psychologist level rather than within psychiatry itself.

> I think that there is some kind of resistances to, or critique of the medical model increasingly within the circles of professionals, as we see for example in the Critical Psychiatry Network, which is I think is quite hopeful. Now I'm not saying that the dominance of the medical model has ceased but I think it's interesting that we see resistance, and we see critiques of the medical model by, you know, the very people that one would expect that they would be supporters...Of course this is just a small number of people perhaps compared to, you know, the number of clinicians that work with service users and all that...we see some resistance that's all.

> Well I agree to some extent particularly psychiatrists tend to follow the medical model, but other workers, usually social workers, are more about the person as a whole. And I guess that is like more of a social approach.

> Some service users accept a medical understanding and approach to their issues and some health professionals adopt a wider social model of understanding...There are differences within both groups...However the mental health trusts and an increasing number of professionals are moving away towards a more holistic approach. There is a sea of change slowly beginning fortunately. Nurse education also adds towards this new approach although in my experience psychiatrists are more embedded in old thinking.

I think it is changing. I have generally been able to find a GP who had a social approach and most of my friends share that view.

I think that was one of the big changes for me. I've suffered, as I said, currently and I've had episodes in the past, and when I came out of this hospital this time, I do think I found, I felt a shift in the way people reacted to me – in a positive way...I suppose more in the social model actually. Just seeing me as an individual and what the barriers would be for me and what they could do to help. And I did feel that very strongly this time.

Ways forward

A key aim of this second stage project was check out the findings from the first stage involving a wider range of mental health service users/survivors in the process and finding out from them how they though discussion and developments about more social approaches to mental health could be taken forward. That is the focus of this final section of this report.

Service users/survivors offered a number of ideas about how the move to more social approaches to mental health could be made. In a number of cases, they raised issues which would both encourage a shift to more social understandings and which would also benefit from such a change – cause and effect were closely inter-related.

Sharing experiences and building alliances with allies

A recurring theme in this consultation was that sharing ideas and experience and including service users at every stage was essential in moving on with social approaches. Making it possible for service users to get together with each other was seen as at the heart of this. Participants took the view that sharing ideas with other service users/survivors and building alliances, people would develop confidence that

would help them to gain a voice and feel valued. This point was frequently made in their comments.

The voices and experiences of service users need to be involved at every stage, including service user led forums and discussion groups.

It would be useful if we had groups like this running at least say once a month, it would be really helpful because we could, you know – this is the way that ideas get together and germinate each other and gradually gets spread out...I think it would make a difference.

I mean I think what's happening now [the focus group] is really good in itself – a social thing... Because the [way] people are going to get their confidence up and challenge some things is through feeling their value and their worth through discussions like this. So more of this stuff needs to be done, because I mean there are groups like 'survivors' in Bristol...if there was more of this, if we could facilitate more of this for service users and survivors, I think you might actually get more of a movement that could challenge the hierarchy.

Keep networking on this and share ideas. Shame holds back many people. We need to make sure they know they are welcome.

Develop firmer networks within the service user/survivor communities about this topic.

Participants saw working with allies in research as a valuable way in which service users/survivors could be included in improving support and services through a more social approach. It would also help to create contacts and solidarity between service users themselves. Such research could help develop and strengthen knowledge and ideas based on lived experience.

I think there is some amazing research out there. So there is something called the ACE study that looked at the link between adverse childhood experiences and adult difficulties, and it's providing this incredibly strong, um, framework for a social model for understanding

adult mental health -problems that's having links in childhood adversity and trauma. So I think we need to make more use of those amazing studies and work that we've got. And that means working with allies more and having more of our own conferences and seminars, and ways of exchanging our knowledge amongst ourselves, so that we're...not just so that we are talking to each other, but so that we're learning from one another and then we can go out into education and other arenas and share what we know with people who are being trained coming up the ranks.

I think it's about working with allies and service user knowledge and service user alternatives.

Research should reflect a wider understanding of mental health than a focus on accepted diagnoses and supposed symptoms, but this requires a democratising of the research agenda and funding, to reflect the different perspectives. Quality measurement should be undertaken by those who have personal experience, not by those who have a professional interest.

Survivor researchers have to keep plugging away at used led research and understandings to issues, and seek to enthuse academics about alternative ways of viewing issues...

Not just discussion – research. There should be a requirement that NHS mental health research departments support such research. It should not just be left to the interests of the people running them. There should also be a requirement that independent service user organisations participate in this and have the opportunity to submit proposals...

Some participants stressed the need to draw more on service user/survivor experiential knowledge in developing training for professionals:

...it's about taking those patient experience models into the training and saying that actually we've got case studies of where a conversation

at a certain time changed somebody's outlook for the weeks ahead, rather than forcing a medication issue, and being aware of the wider issues. It's certainly got to happen right at the very beginning of the training because we all know whenever we undertake any training, you get what's said earlier on in, as there is only so much you can take on board. I think there's a role right across the board to start collating some of the information like we're all getting in here and using that to feed the media and staff training and some of the professional development in other areas as well, not just mental health.

Pressure NHS Trusts to develop training modules critiquing the medical model, targeting mental health professionals/admin staff at the beginning of their career. Ensure these training modules have a 'real' contribution from people with lived experience of mental ill health.

Other service users spoke of the need to support people to share their experiences so that this could encourage broader understanding and reconnect mental health issues and experiences with the mainstream.

It is time for us to look at the 75% of the population who have never been stressed, tired, overwrought, lonely, unsupported – and ask them why they still continually whinge about overwork, insomnia and stress. Ask them what they mean and let them know what it is that they are really expressing...Perhaps if the 75% well could start to identify with [mental health] issues and recognise that if they lost jobs, opportunities and relationships directly because of their stress/insomnia how it would impact on their ability to continue a worthwhile life?

So I think it's about, you know, we share experiences, they'll be a better understanding and I think that can only help really.

Using people to share experiences and normalising it far more.

The positive employment of mental health service users

Public discussion about employment issues in relation to mental health service users has mainly been framed in terms of 'welfare reform' policy and efforts to get people off benefits. Service users here instead spoke of the need for a greater commitment to employ people with mental health issues positively at all levels.

> Employers should have more of a duty to employ people who've been through disability. The two ticks symbol only requires them to give us an interview, which can of course lead nowhere.

> Charities and campaigning groups must employ the mentally ill at ALL levels. This might be obvious but it is shocking how many groups do not have a substantial amount of mentally ill people on their board.

Some service users also emphasised that if the workplace is to be made more inclusive for service users, then they will need to be offered more support.

> What I suggested to my mental health team was that they might consider, when they send someone along to a book shop or a charity shop or to any other organisation to work – it might be a good idea to have a conversation that says. 'Let's establish some [parameters] so that we know if this person becomes ill to a certain degree then we'll suspend his employment or we'll give you a nod to do so. And then he can go away and be unwell for a while or be hospitalised or whatever the path takes, and when all of that's finished and done with, he can come back and continue employment'. But I don't think the mental health team have taken that up because they've said, 'Well we want you to be independent, so it's up to you to negotiate with the employer and to deal with the employer and so on'. So it's a question of finding the balance within all of that to help to break down some of the difficulties that do exist…

> Unless they do something like, you know, if you go for a job interview…like if there's somebody who's been in prison for 10 years or something… if they got to the interview stage and then they're asked questions like, 'What have you done for the past 10 years, Why is there a gap in your CV?'. If they did something like that with people with mental health and mental distress, a scenario like that and then have a person squirming and feeling uncomfortable that would show the effect of discrimination, and how that person doesn't end up getting the job. But then the converse to show how a mental distress situation…could be used in a positive way…the same person could be interviewed with a different employer maybe…So you see two sides of the same story…then to highlight it and show how the positive can be used in a positive way. So something like that.

Changed priorities for funding

A number of service users thought that if more social approaches were to be taken forward effectively, then there would have to be changes in mental health funding. There was a sense that current funding policies were working in the opposite direction.

> In terms of policy and in terms of practice, we have seen particularly in the last few years, like a vicious attack on mental health services in terms of funding cuts…like mental health services are understaffed. There are all these sort of cuts to welfare benefits and I think that all these things do not actually help towards embedding more social approaches into our lives…It's like a paradoxical thing where, you know, on the one hand, yes, there is all this rhetoric around recovery on the Government for example…And on the other hand, we've got the sort of cuts through funding cuts. And all that have detrimental effects on people lives… and I'm not sure how far for example, you know, the Government in the country will go in terms of embedding social approaches in policy and in curricular, whilst at the same time you know all this is really undermined by funding policy.

Funding, some participants argued, needed instead to be directed towards enabling more participatory services A major theme that emerged was that service users must have more control over their own health and well-being. They needed to be listened to and should be able to make informed choices for themselves.

> So it's about self-determination and also choice is the most important thing. We decide what's good for us.

> And you don't have to do that because services have been taken away suddenly. You do that because you are moving towards doing whatever it is you want to do.

> The medical professions need to listen to the clients, and from the clients point of view they are complex, because they are not given their own voice, they are not given the opportunity to express how they are feeling. And if they are admitted into hospital then of course they need medication so the client is led to believe that the only way out is medication. It's a no-win situation and I think one of the biggest problems is not being listened to and them thinking that, 'Oh because you've got a mental health issue, you cannot express yourself, you are not to be listened to', so the multi-disciplinary team make the decision for you.

> I think there is a huge body of evidence now that shows when you involve service users, patients, carers in the design and development of services, they're more effective and people use them more effectively. My own view is that mental health probably has a greater opportunity to learn from service users than any other service, because it is about using patient stories to explain about these barriers between the medical and social model and the fact that when you have been patched up from your crisis what are the things that are still difficult when you finally get thrown out the door of the hospital and you're on your own in the community with limited support, or whatever. I don't think that there's a full appreciation of that and I think actually utilising patient stories could help with that.

> One of the consequences…of having an episode or continual breakdowns in terms of mental health problems, is that people disengage with society and they try and remain in isolation, and to be able to try and reintegrate them back into society that is why it is very important to have these social approaches. And if you are to give them free choices – any particular client, saying, 'Look you've got a choice here – you can go and have some medication, here is a group where you can have a lunch and a trip to safari, here is a group you can go to lunch and go to cinema, try and work out for yourself which one'. I can guarantee that you would have the least amount of people going to get the drugs.

> …people aren't actually told always unless they go to places like local charities or whatever, to get help or you know peer support and stuff like that, but the ones that are isolated and only on medication how are they going to know what else is out there, that's where people need to advocate for the social side I think.

Implicit in many comments was that a more social approach to mental health issues was inseparable from more user involvement in policy, practice, services and training. And for people to have real choice and control over what service and support are best for them, service users stressed that there has to be increased and more secure funding. A standardised traditional system of services cannot meet the needs of everyone. Inadequate funding and a generic approach cannot effectively respond to each person's needs.

> And you need the facilities to be able to do it. And you've got to have enough money to run them.

> But we need more funding. We're not getting enough funding for what we do and what we require. We need money to be able to function.

Some service users highlighted that the distribution of funding also needed to change. As one service user put it:

> I think there needs to be more funding really for these groups, like mental health groups, and to let them get on with what they want to do kind of thing. There's not much…you know, funding has dried, I know lots of groups who have just ended because of the funding really. And you're not talking like millions of pounds, I'm just talking a few thousand here and there, it's not a lot.

For funding to reach small organisation there needed to be a fairer system of funding which would give small local charities a real chance of securing support. At present there is far from a level playing field as far as funding allocation is concerned.

> And also some of the well-established voluntary organisations, they have special fundraisers who articulate funding applications so well that people like us…we have no chance.

> Yeah, we have no chance.

> …We can't have professional fundraisers, so how's our bidding possibly…even going to be heard.

> Yeah.

> They need to come and see the work and not the paper.

Many participants made the point that different kinds of economic arguments needed to be considered than those currently adopted, based on more appropriate models of cost-effectiveness, that took into account longer term economic and human costs.

> It doesn't necessarily cost more money but the society that we built is like a bicycle, it can't stay upright when it's static. The economy, if it doesn't grow all the time, more and more Starbucks opening everywhere, more and more people spending money…it can't keep going and we're trapped in the cycle which is

always going to put financial efficiency above humanity. Somewhere we've got to stand up and take humanity back as being a priority, rather than making money as a priority.

> …all of these – cost effectiveness – are seen as a short term things. So we're looking to the election, so if you invest in schools or whatever – by 2015 will that have worked?…if you actually looked at that over a life time basis, you would say let's help these young kids because in 30 years' time…if you actually invested in building a rounded humanity in proper communities, then it would be cheaper.

> So it depends what resources are spared and used properly, invested in people. If they treat service users as people – human beings who deserve love and care and be looked after, rather than, I don't know as 'mad, bad and dangerous', as scum of the earth to be just locked away and shoved away forever. If they use the resources properly, people could be rehabilitated back into society and live proper and fully rich lives and be contributors to society as well. So the approach has to be different.

Early interventions and promoting alternatives
Some participants drew a connection between more social and more preventative approaches to mental health policy and provision, seeing the two as closely interrelated. Some service users felt that there is a need for better early interventions for people being referred to services. This could help many people avoid reaching a crisis stage.

> I think if we could have early intervention with psychological therapies and so forth for people and they would be referred within, what it is it – 28 days – someone's trying to bring in a new law and they're hoping to get it passed.

> I think about war and pacifism. Once you put all your money into armies and weapons, you stop trying to solve the problems so it's got to the war stage and then you get into a war. So maybe there's a comparison really, with like

helping people before they get that distressed, putting your resources into stopping people getting so distressed before they're running amok with a machete.

Yeah, I think that if people are encouraged that when they start to feel symptoms that they can't cope and everything else, that they should be encouraged to come and see their GP, get referred and if they do it sooner rather than later, surely it would actually help. The sooner you nip it in the bud.

The point was strongly articulated in discussion:

The only way is to be more ill and then they get support. So they're saying crisis is the solution. Crisis is not the solution.

You need prevention.

Prevention is the solution.

In another discussion, service users' highlighted the perverse way in which the existing rationing system for support worked.

...The people who are very 'substantial' or 'critically ill', they are the recipients of the personal budget right. So now the situation where people are 'mild' to 'moderate' [according to existing eligibility criteria]. they don't get a budget so they cannot socially go anyway on the budget right. So what happens? The Tsunami is this – the people who are moderate they become sick or critical before they can get it. So you know its not working that thing really.

The system's not working.

People need to look at people who have recovered. They need to be supported by [a] better budget. OK, they may get a smaller budget, [but] that budget should be given on a [basis of] need – again for 'mild' to 'moderate' also. [A] personal budget which is only for 'substantial' or 'critical', just does not work. I n fact it leads [to people who are categorised as] 'mild' to 'moderate' to go into crisis. It is a negative effect.

A more appropriate welfare benefits system
Some service users felt that a more social approach to mental health issues was unlikely to make major progress so long as the welfare benefits system continued to be based effectively on a medical model. Thus disabled people, including mental health service users, continue to be assessed on the basis of what they cannot do, rather than what they can do. Service users have to demonstrate deficiency, deficit and incapacity to get support, rather than support being offered to support them to achieve their full potential. The present welfare benefits system, framed mainly in terms of physical and sensory impairments, creates additional problems and barriers for mental health service users. In the project some participants highlighted the importance of having a benefits system that moved beyond such a narrow medicalised model. The present system does not readily recognise 'hidden' impairments and in order to secure financial support people must be recognisably and significantly 'ill'. This in turn reinforces stigma and negative stereotyping. Thus a benefits system supporting of a social model of mental health needed to:

• Recognise and value issues of distress
• Take account itself of the barriers facing mental health service users
• Challenge rather than add to the hostility and discrimination faced by mental health service users/survivors

There needs more of a voice from support organisations and local government against the demonization of people on benefits. You know with the ATOS [the organisation which has undertaken disability benefits assessments], unless you go in and you are foaming at the mouth but if you go in and you sound like a sensible human being, then you can work. Okay, so it's really about hidden disabilities in mental health, there are a lot of hidden disabilities around...I think the problem is when you keep having to explain to somebody that you can do this or you can't do

that about your disability and they can't see it... so you're feeling like you have to justify yourself. That is a stigmatisation or whatever is happening, you have to justify yourself and people not believing you if you look OK.

As for benefits, one would have to substantially change the descriptors to include symptoms such as distress, hallucinations.

There should also be a fairer benefits system which doesn't operate in such a medical model kind of way – i.e. have to be virtually unable to do anything for yourself. Benefits should be about living and promoting independence.

Lobbying Government against further social care cuts, and lobbying local authorities to pool their money with the NHS to fund new social approaches.

Some participants said that a benefits system was needed that promoted independent living and a good quality of life. Benefits and support should not be tied narrowly to economics. Instead people should be supported to achieve goals and their contributions, such as voluntary work, should be recognised rather than devalued.

Voluntary work accepted as a real and valid option, so people can feel part of society and do activity without fearing they lose their benefits.

One of the big barriers for mental health service users (and ex-users) is that unlike physical disability activists we cannot be open, named, on the TV, radio, in print, be public anywhere near as easily, because to even be seen as able to string a sentence, invalidates any claim to social support...Only nine per cent of secondary mental health service users are in paid employment. This makes welfare reforms especially cruel because the chances for many of us of ever getting into work are slim. This is why welfare needs an additional outcome – voluntary work OF CHOOSING – in recognition that some people will never progress further than that because of societal prejudice and

corporate inflexibility, and because some of us actually need that. Mental health service users have some of the highest levels of voluntary work of all disabled groups which NHS Trusts, charities and universities benefit from. That is a valued contribution, and should be supported by welfare policies.

Addressing ethnic and cultural issues

Finally, service users highlighted that the narrow focus of a traditional medical model of mental health, with its emphasis on the individual and personal pathology, significantly failed to address cultural and ethnic differences.

A number of service users taking part in the project made it clear that they thought that services need to develop better understandings of people's cultural and ethnic backgrounds. They felt that reliance on a medical model hadn't helped here and that a social approach would encourage such understanding.

it can show you the work that the medical profession have to do is so wide. You have to put religion into consideration, culture and background, race.

We can't just think about the 'little UK'. This thing is much bigger than the UK. And when we see that a lot of this is being – the Western model of you know, what it is to be ill, or etcetera, etcetera, is pushed onto cultures which have a completely different understanding and experience.

Discussions like the following highlighted concerns that mental health services needed to do more to address the needs of black and minority ethnic service users for them to feel adequately supported, included, safe and that that they had real measures of choice and control.

When you put generic service one side and a cultural service one side, you will see service users going to cultural side.

Absolutely.

> Generic services – so instead of even doing the prevention work actually people are ending up in hospital which is more costly.

> Yeah.

> It isn't segregation, it's just that people have certain cultures.

> Yes!
> We grew up on a certain amount of food. We speak a kind of way. We have certain things in similar. It's not segregation...

> No, it's cultural. There's no racism in that.

> No, nothing like that.

As these service users said:

> The things that are offered need to be culturally based for that particular client base – whether they are from Africa, whether they are from the Caribbean, whether they are from Asia. What is it in the culture that they normally do and here's some of the counselling around that. I think one solution doesn't fit all.

> ...I have worked in this particular area about safe spaces. So in a lot of cases people feel more comfortable to be in their own community, they come to a day centre, for example, you know. There are certain projects which are like community based projects, so for example we have a South Asian group, so that I consider as a safe space for people to come to. But at times the psychiatrist or the community mental health team might say 'Well you go to so and so day centre'. They may not like that day centre you know. So, you know, sometimes this thing about integration is a good idea but integration only takes places when they're ready to integrate. You can't force people to integrate you know. So projects which are based on community level should be encouraged really...

Some people talked about the need for religious practices to be recognised and understood to prevent further discrimination and misunderstanding around people's behaviour.

> This is very similar to some of the South Asian communities because when you first wake up you do chanting, right, mantras. And I've heard where people have started chanting in the morning – 'All these are now hearing voices and gone crazy' [can be the response], you know come on give him [an injection]...

> Sectioned...

> ...and that is really important that people should...If you're nursing someone whose not from your culture background you really should try to understand what they're religions are, what their beliefs are, what they favour. If you don't do that you won't get nowhere.

To enable services to be more supportive and understanding they must better represent the client groups.

> Also councils. Someone in the workforce who understands our culture.

> Yes.

> Yes.

> Very true it needs to be rebalanced.

> So basically when you are employing someone for a job, [to be] especially aware of your constituents' concerns you need to put all this into consideration. And just a qualification...it got to be culturally diverse into part of that qualification, to make sure that the person who is being employed...must fully understand.

They also highlighted the need for an understanding of language issues and barriers:

> In most cases where the first language happens to be in a lot of cases English with South Asian communities and maybe other communities there are not able to raise their voice at all because they cannot articulate. They may know a little bit of or a few words in English – they are even more vulnerable.

Such broader understandings would also need to be included in service providers' training. Workers need to go out and see what work groups are doing and value it. These points were strongly made in one group discussion.

> It must be in manager training. It must be manager training that they go through, even psychologists. Manager training and learning to deal with certain client groups you know.

> ...we cannot be blamed if we think inversely they are racist. You see what I mean. Because we are not getting the funding...is it because I'm black, you know, or is it because it is a cultural thing. So they write down, 'Oh he's going to this centre', so they think we're racist but actually it's them that's racist you see what I mean, because they are not funding what is so obvious and right in their face. So why can't you get the money [if you are a BME organisation or group] – if people go to this cultural centres and they getting better, it's pretty obvious that that is what is working.

> Yeah, yeah.

> Yeah, that's why I think, you know, the suggestion that the whole thing needs to be told rather than things coming from the top. The professionals need to go to classes to see what is working.

> Absolutely.

> And then bring it out from there and go that way round, rather than filtering it from the top, take it from the bottom.

Finally, as one service user said, there needs to be recognition of such structural issues at every level on a day to day basis, if traditional medicalised individual models are to be challenged by a more social approach:

> And that is how it is, you know, they judge you before you even come. They have all the papers on you, all the files ready...especially on a ward. Sometimes you hardly see an advocate from a BME community, even high up within the trust, you hardly see. So I see the staff who send me to the ward and sometimes I go to meetings... I see most of the time service users and I want see a reflection in that from the top coming straight down.

CONCLUSIONS AND RECOMMENDATIONS

The first point to make about the findings from this second stage project is that generally they are closely consistent with those from the first stage. This is particularly important and helpful because those findings were themselves not always predictable or in line with existing assumptions. But the findings here make it possible to flesh them out even further and to have an increased sense of confidence that we can place serious reliance on them.

Valuing a social model, rejecting the medical model

While participants in this project offered detailed and nuanced views about the conceptualisation of mental health issues, it is clear that most regard the conventional medical model of mental health/illness as damaging and unhelpful.

Instead there is a widespread and largely shared view among them that more social approaches are much more helpful. We know that this reflects a broader increasing interest in such social approaches. Yet so far this has not had a serious impact on policy, practice, services, thinking or research in the field of mental health. Instead if anything, the medical model and an ever-growing range of diagnostic categories seem to be expanding in influence, with pressure to interpret and respond to a growing range of social issues and problems in medicalised individualistic terms.

Hopefully these findings will provide a timely wake-up call, from the horse's mouth – from the experience of mental health service users/survivors themselves – to take forward more social interpretations of mental distress with greater determination and speed. The continued efforts of organisations like the Social Perspectives Network give force to the need for this.

While the headline message from this project like its predecessor is the strength of service users' concerns about conventional medicalised understandings of distress and their belief in more social models, there are at least three other important issues that emerge from the project.

Language problems

First are the problems of language that continue to constrain both understanding and progress in the mental health field. We still have a very limited and unhelpful vocabulary for 'mental health'. This emerged constantly in the project. Thus participants who were critical

of the medicalization of distress, nonetheless frequently themselves used medicalised language, for example, talking about 'mental illness', 'mental health', 'mental health problems'. On the other hand, the concept of 'recovery' seems in practice to be an extension of a medical model, yet some mental health service users/survivors espoused it because of the hope they invested it with. Indeed language has been an issue for us too in writing in this report. We have found ourselves having to use medically-based terminology despite our own reservations about it. This is because there is no agreed language in this field and what one person favours may offend another. If we might feel more comfortable talking about 'madness' or 'distress', as is very clearly demonstrated by some of our participants, 'madness' is a term that has become to degraded and perjorative for some survivors to consider using it. On the other hand some service users and allies internationally are now determinedly using the term under the banner of 'mad studies'. This sets out a new marker for those seeking to challenge the medicalised models that service users generally dislike and find unhelpful. Language in mental health that demands further consideration, if we are to be able to talk safely and without misunderstanding to each other. We should also remember that terms like 'black' and 'gay' were initially rejected and sometimes ridiculed.

Recovery: a problematic policy

Second, 'recovery' does not seem to offer mental health service users/survivors a convincing alternative to traditional mental health policy and philosophy, even though it has been officially adopted as a big new idea. The distinction some participants in the project drew between the idea of recovery – which they felt held promise – and the policy – which they largely see as negative and unsupportive – is a helpful and important one. 'Recovery' has been used in practice as a rationale for reducing

support and cutting services as well as driving service users off benefits in a harsh 'one size fits all' way. The lesson from this study is that this has seriously undermined any credibility it had with service users and their organisations.

The shortcomings of anti-stigma campaigns

Third, anti-stigma campaigns, which have come to command major public and political interest in the UK and beyond, gained a very mixed response from mental health service users/survivors in this study. The evidence internationally is that they are not very effective, resulting in very limited improvements in public attitudes. While some service users who took part in this project felt they could be helpful, others were much more critical. They tend to be based on a model of 'educating the public'. Ironically some of the heaviest stigma currently is coming top-down from government, as a result of the presentation of mental health service users and disabled people as scroungers in welfare reform policies and associated media welfare claimant campaigns

The social model of disability

Mental health service users' views are particularly polarised around the social model of disability. It generates significant controversy among mental health service users/survivors, as we found in the first stage project. For many, is not readily transferrable to their experience, even though the issues of oppression, discrimination and barriers it highlights make sense to them. Views are particularly divided about the concept of 'impairment', which some feel is alien to their situation and experience. There is an irony in that disabled people developed the social model to escape from the prevailing medicalised individual model of disability, but for some survivors, the concept of impairment feels like a re-imposition of a

medical model on them which treats their experience like a physical or chemical problem. A key lesson it seems we should learn from this is that social approaches to madness and distress are likely have massive traction with mental health service users/survivors, but not if they are narrowly based on the social model of disability. Some participants in our project (indeed like some disability commentators) also feel uncomfortable with drawing over-simplistic distinctions between the personal and the social; the psychological and the social and highlight the need to recognise the interactions of the two and the value of an holistic approach.

Recommendations

- The findings from this project should be shared as widely and effectively as possible, particularly among mental health service users, their allies, workers in related fields, among researchers, educators, policymakers and in mental health professional education.

- Organisations which seek to speak for mental health service users/survivors and advance their rights and needs, must begin to look much more critically at their own adherence to and perpetuation of medical understandings of mental distress which many service users find damaging and unhelpful.

- More support should be given to organisations and initiatives like the Social Perspectives Network which are building understanding and evidence about social models of mental distress and mental health.

- Discussion about the social model of disability in disability studies and among disabled people should take account of the issues raised by mental health service users/survivors about its application to their lives and experience and explore their implications both for the social model itself and for mental health service users more generally.

- These findings signal the urgent need for extensive and more sophisticated discussions about social approaches to mental health issues which fully and equally include mental health service users.

- These findings should also be considered in relation to the emerging international discipline of 'mad studies'.

- A different funding approach is needed in mental health policy, which ensures that adequate and secure funding is redistributed to reach smaller community based, BME and user led organisations (ULOs), which encourage user involvement and show a greater understanding of social and holistic understandings of mental health/distress.

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APPENDICES

Developing service user/survivor ideas on social approaches

Introduction

This survey follows from a project about service user/survivor thinking on social or non-medical approaches to mental health issues.

We want to take it forward by asking you what you think about what we have found so far.

to begin with it might help if you read through our definitions of the medical model, social approach and social model of disability:

Medical model of health and illness - a short description:
Something is wrong with a person - this model is based on the idea that health problems are found in an individual defect or pathology.

The medicalised individual model of disability (the traditional way of thinking about disability):

This locates the 'problem' of disability within the individual and sees the cause of this problem as coming from the functional or psychological losses that are assumed to arise from disability. The process is seen as a personal tragedy for the individual and framed in terms of pathology or deficit. In summary, there is something wrong with the person; their arm/leg/sight or brain doesn't work - or something is missing.

Social approach to health and illness: illness, distress and mental health problems are linked with social factors. Social factors play a part in causing the problems and have to be addressed if people are to be ok

Social model of health and illness and disability - stronger than the social approach:

Social barriers, attitudes, exclusions and discrimination are key problem that needs to be addressed if people with health issues are to participate more equally in society

The social model of disability emerged from the disabled people's movement. It draws a distinction between individual impairment and a disabling society.

The individual may experience or be seen to have an impairment. However, disability is the negative social response to such perceived impairments.

Disability is taken to mean the problems created by the barriers, discrimination, restrictions and other negative social responses that are directed at people seen to have or identifying with impairments (eg hostile and stigmatizing individual and institutional attitudes, inaccessible environments, transport, culture and communication, etc).

So apart from any difficulties that a person may experience as a result of an impairment, they can expect to experience additional problems as a result of the societal response to it.

The social model locates the problem of disability in society, while not denying the potential problems of actual/perceived impairments or complex relationships between the two.

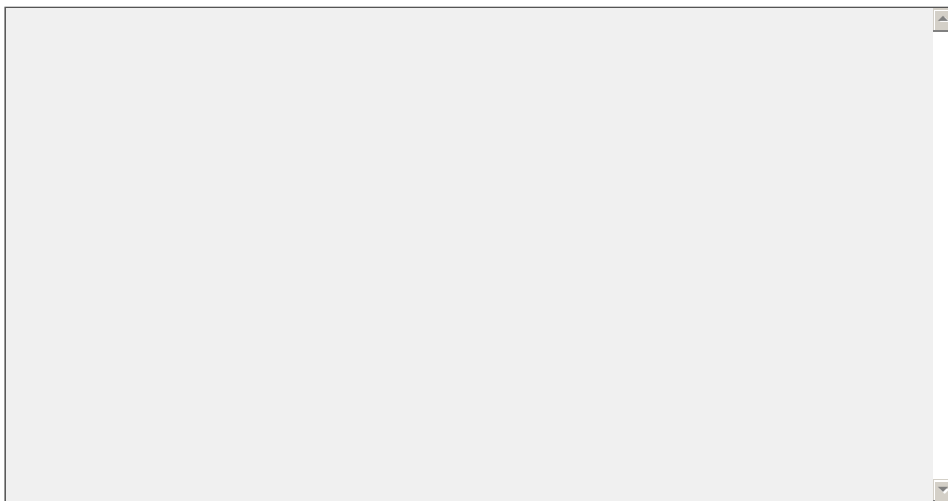## Developing service user/survivor ideas on social approaches

1. Most service users believe that the public and professionals see mental health as a medical issue (the medical model). Do you agree this is the case?

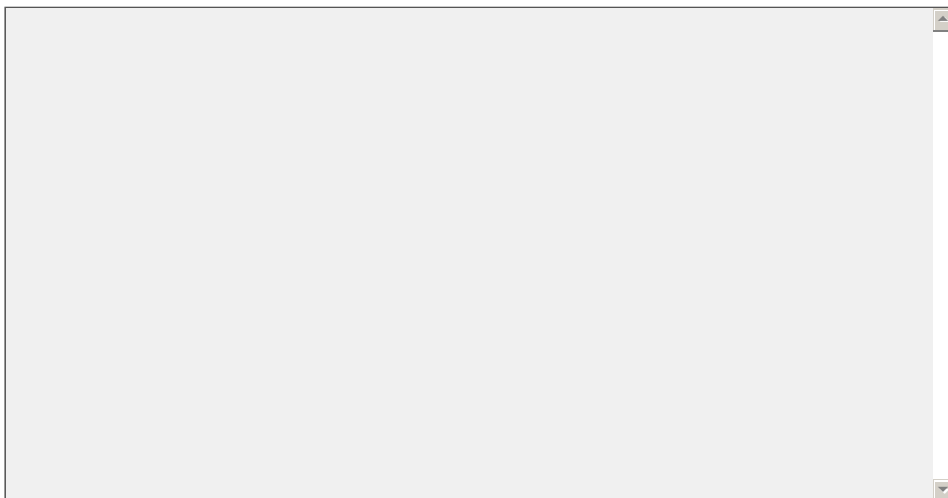○ Yes   ○ No   ○ Don't know

Further comments on this question

2. Service users answering our original survey think that it is common for mental health service users to accept and internalise (come to believe in) the medical approach to mental health. What is your view of this?

○ Agree   ○ Disagree   ○ Don't know

please say more about this
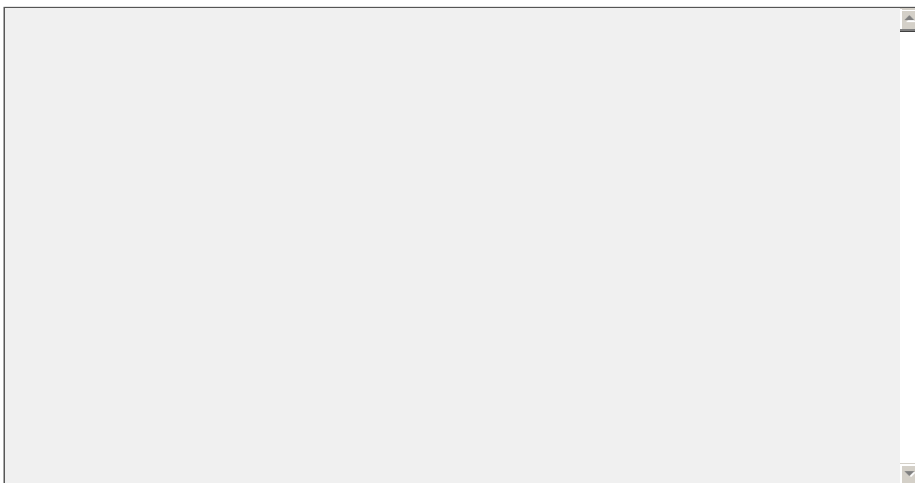
Developing service user/survivor ideas on social approaches
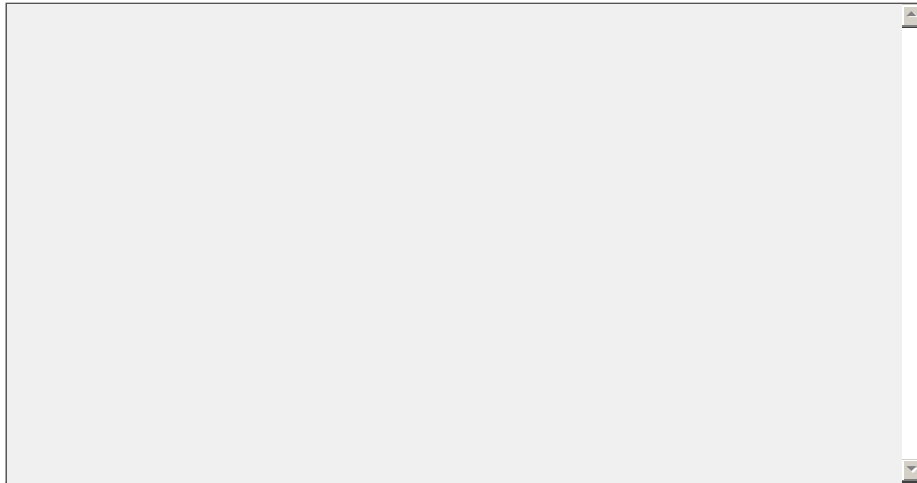
3. Most service users answering our survey said they see the medical approach to mental health (the medical model) as damaging and stigmatizing. What is your view on this?

○ Agree on the whole   ○ Disagree on the whole   ○ Unsure
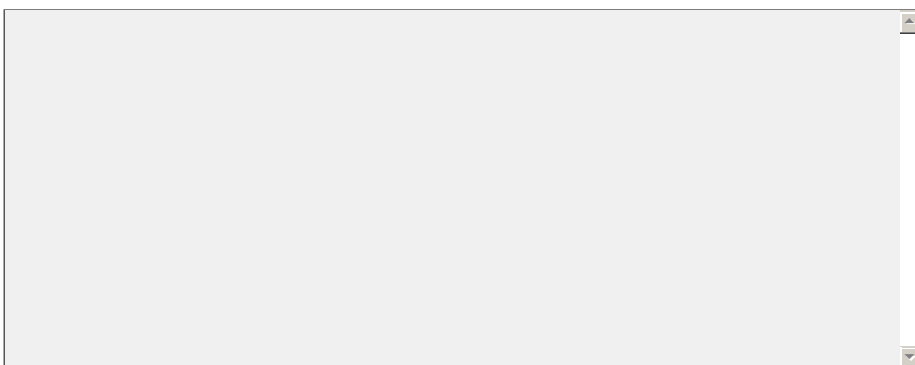
please give your view about the medical model

4. If reclaiming the word 'madness' helps us as survivors to move on from the medical model do you think it is helpful for us to do this?

○ yes

○ no

○ not sure

Further comments

Developing service user/survivor ideas on social approaches

5. Service users said they thought social approaches to understand and help people with mental health problems were the best way to go. What do you think?

○ Mostly agree   ○ Mostly disagree   ○ Unsure

Further comments on this question

6. Service users questioned think that social approaches to mental health problems would take into account wider issues, such as the barriers, stigma and discrimination experienced by mental health service users, instead of just looking at what is wrong with the individual person. What is your view of this?

○ Mainly agree   ○ Mainly disagree   ○ Not sure

please say more about this

Developing service user/survivor ideas on social approaches

7. Do you think it would help if there were more discussion on social approaches in mental health and more challenge of exisiting medical approaches?

○ Yes   ○ No   ○ Unsure

How could more discussion and challenge be encouraged?

Developing service user/survivor ideas on social approaches

8. Do you have ideas on how greater openness towards social approaches in mental health could be built into professional education and training, professional practice, policy, the media, research and quality measurement?

The social model of disability says that disability is caused by the way society is organised, rather than by a person's impairment or difference.

It looks at ways of removing barriers that restrict life choices for disabled people.

When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives.

Disabled people developed the social model of disability because the traditional medical model did not explain their personal experience of disability or help to develop more inclusive ways of living.

(An impairment is defined as the limitation of a person's physical, mental or sensory function on a long-term basis.)

Mental health service users/survivors seem to have mixed feelings about the social model of disability and whether it can be helpful for them.

Some don't like being identified as disabled people, while others are ok with this.

Some don't like the idea that they have an 'impairment' – that something is wrong with them.

Others feel that linking with disabled people makes us stronger and more difficult to attack

Others feel that the social model of disability is helpful because it highlights barriers that stigmatise

and discriminate against mental health service users same as disabled people.

Developing service user/survivor ideas on social approaches

9. What is your understanding of the social model of disability as applied to mental health?

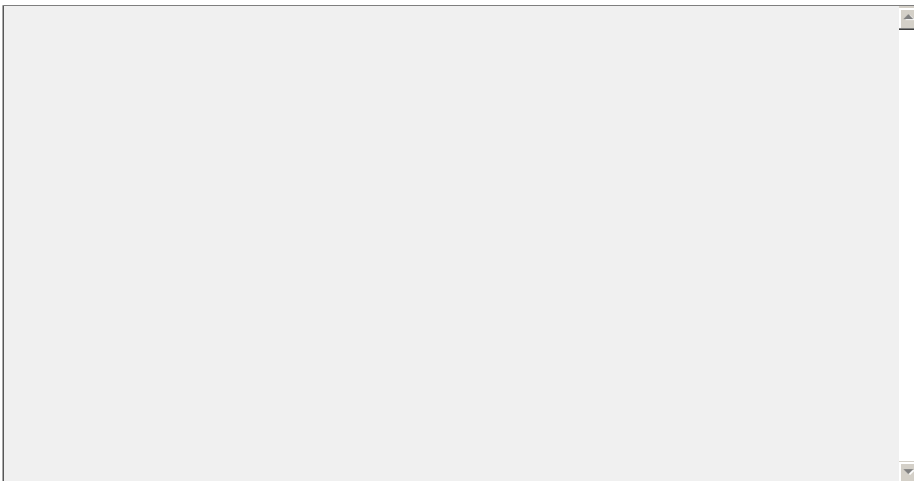○ Broadly in favour of this   ○ Broadly not in favour of this   ○ Don't really understand it.

please say more about what you think

10. Do you think that the social model of disability and closer links with disabled people can help make mental health service users stronger as a collective group?

○ Yes   ○ No   ○ Unsure

please say more about this

Developing service user/survivor ideas on social approaches

11. What do you think about how to draw attention to the barriers, discrimination and stigma that mental health service users face and challenge the way they are excluded eg from employment, benefits, opportunities and relationships?
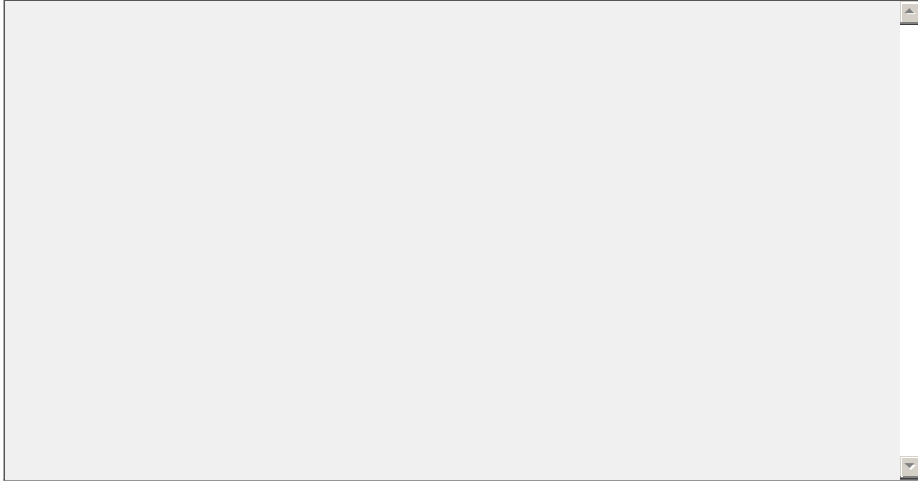
12. Do you think that the idea and policy of 'recovery' is working out to be helpful for mental health service users/survivors?

○ yes
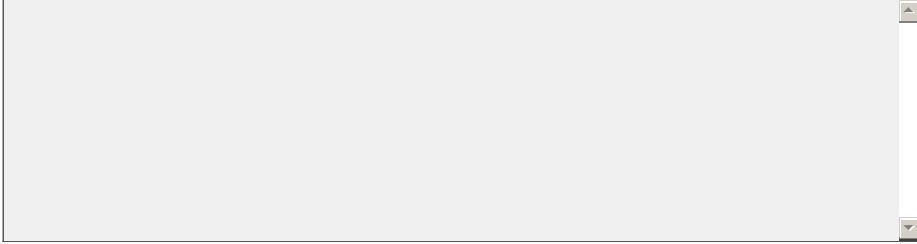
○ no

○ not sure

Further comments

Developing service user/survivor ideas on social approaches

13. Do you have any more to say on the importance of the issues raised in this survey, that is: how do we achieve more effective action towards social approaches and effective campagning by service users?

Developing service user/survivor ideas on social approaches

14. Thank you for taking part in this survey. Please let us know if you would like a copy of the report. Please leave your name and contact details if so.

Demographics of focus group and individual interview participants

How participants identify	
A mental health service user / survivor	27
A mental health service user / survivor and a disabled person (by reason of experience as a mental health service user)	9
Do not identify as either	1
Undisclosed	3

Participants by gender	
Male	17
Female	20
Transgender	1
Undisclosed	2

Ethnicity	
White British	18
White Scottish	1
White Irish	1
Black British:	
African	3
Caribbean	5
Asian British:	
Indian	4
Pakistani	2
Bangladeshi	1
Other ethnic group: Other White background Jewish white European	1 1
Undisclosed	3

Area	
South West	7
South East	11
West Midlands: Urban Rural	8 8
North West	1
North East	
Scotland	1
Wales	1
Undisclosed	3

Age	
21-30	1
31-40	10
41-50	7
51-60	9
61-70	7
71-80	1
81-90	1
Undisclosed	4

RESOURCES

Shaping Our Lives

Shaping Our Lives is an independent national user controlled organisation, think tank and network. It has a stong committment to diversity, equality and inclusion and works to increase the say and control that people have over their lives and support,

For more Information about Shaping Our Lives and other resources available free to download, please see:

www.shapingourlives.org.uk/resources/our-resources/all-publications

NSUN

NSUN network for mental health is an independent, service-user-led charity that connects people with experience of mental health issues to give us a stronger voice in shaping policy and services.

For more information about NSUN please see:

www.nsun.org.uk

This report, supported by the **Joseph Rowntree Foundation**, explores mental health service users' views and ideas about models of madness and distress.