

**OUR VOICE IN OUR
FUTURE:
MENTAL
HEALTH
ISSUES**

Peter Beresford

**Shaping Our Lives/
National Institute for Social Work**

Our Voice In Our Future: Mental Health Issues

Published 2000

by Shaping Our Lives/ National Institute for Social Work

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This booklet is distributed free to people who use services as part of the Our Voice In Our Future project which aims to give people who use services and receive benefits provided through the welfare state a say in their future.

The Joseph Rowntree Foundation supported this publication as part of its programme of research and innovative development projects, which it hopes will be of value to policy makers and practitioners. The facts presented and views expressed, however, are those of the author and not necessarily those of the Foundation.

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ISBN 1 899942 40 8

Cover designed by Pat Kahn

Printed by Meridian Print Centre Ltd, Derby.

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Acknowledgements

Thanks to survivors Mary Nettle, June Sadd and Anne Wilson and to Michael Turner and Margaret Hogan for their suggestions and comments.

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Summary

Introduction

Our Voice In Our Future is a project to give people who use services a say in how they change in the future.

There are three booklets: one on benefits, one on services and support, and this one.

The booklets tell you what changes have happened already and the changes that are happening now.

We want to hear what everybody has to say about these things.

We are also talking to people in two areas to find out more about what they think.

Not everyone will agree with what we say but we think that it is important that users have a bigger say than before.

Our Voice In Our Future is part of a project called Shaping Our Lives. The Joseph Rowntree Foundation gave us the money to do this work.

Mental health issues

There have been two big changes in mental health services in recent years.

The first was the introduction of care in the community. This was meant to enable mental health service users to live in their own homes and neighbourhoods with suitable support instead of going into or staying in hospital.

The second is the development of the mental health

service users/survivors movement. This has made it possible for service users to speak for themselves, say what they want and to try and improve the way they are treated.

Current provision

Both welfare benefits and mental health services are important for service users. The level of benefits such as income support is low. Because of this it is crucial for mental health service users who are eligible to secure disability benefits.

Although these benefits are important to maintain people's quality of life, they are generally difficult to get and may be difficult to keep.

Mental health services are provided by health and social services through 'care management' and the 'care programme approach'. Underfunding and problems of coordination mean that the support service users receive is often inadequate, inappropriate and unreliable.

Unlike most other social care service users, mental health service users/survivors are liable to have their rights restricted and may be subject to legally sanctioned detention, compulsory 'treatment' and control over their lives and opportunities.

Black and minority ethnic service users

Black and minority ethnic service users face particular discrimination within the psychiatric system. They are more likely to be subject to control and less likely to receive its better services.

African Caribbean young men are at particular risk of

being diagnosed as 'psychotic' and (with Irish people) of being kept in locked and secure provision.

Refugees and asylum seekers are particularly vulnerable groups and now face increasing stigma and hostility because of government policy and media campaigns.

Current plans for mental health services

The government says that care in the community has failed. Present proposals for mental health policy and practice place a special emphasis on the danger and risk from mental health service users and the importance of safeguarding 'public safety'.

Provisions for more compulsory 'treatment', including the extension of compulsion to people living in the community and locking up people labelled as having 'personality disorder' who have not been convicted of any offence, are planned.

Users' views of proposed changes

Service users have so far had little or no say in the government's proposed changes.

They fear that these will result in their rights being further restricted and being subjected against their will to damaging treatments.

They fear that because of this, many service users will try and avoid mental health services at any cost and be denied any support.

They fear that government mental health policy will increase rather than reduce social exclusion as it is meant to.

They say that 'welfare to work' policy is pushing them off

benefits without adequate support and forcing them into inappropriate and stressful employment.

Users views on alternatives

Some service users/survivors and their organisations are rejecting the conventional medical response made to them. Instead they are developing their own user-led approaches to improving the quality of their lives and the support they receive.

Service users value holistic approaches to support, which take account of all aspects of their lives, including the emotional, material and spiritual. For most people, being prescribed drugs, especially on its own, is not the answer.

There is a growing interest among survivors/service users in a rights-based approach to improving their lives. They are looking at how the Disability Discrimination Act, direct payments schemes and the new Human Rights Act may safeguard their rights, improve their quality of life and reduce the discrimination they face.

Some mental health service users/survivors are developing new forms of direct action in order to bring about reform. They are also exploring social approaches to madness and distress (as disabled people have to disability) to replace old ideas about 'mental illness'.

Introduction

This booklet is part of the Our Voice In Our Future project which aims to give people who use services and receive benefits provided through the welfare state a say in the Future.

It is one of three booklets which will give people background information on three key areas of discussion on future social policy. This booklet covers issues about mental health. The other two deal with services and support, and benefits.

The booklets aim to help people think about the changes that are taking place and being planned to the services and support that are vital to their lives. The people running Our Voice In Our Future believe that people who use services and receive benefits have some of the most important expertise on these issues. We believe that any plans or changes that are made without talking with us first are unlikely to work or improve things.

Each booklet ends with a section called Issues for Discussion – you can use this yourself, or with friends and people that you meet or work with, to think about what you want to say about these issues.

We also hope that wherever possible, organisations that represent service users will send us their views on these issues (where organisations have existing policy documents on these issues we would be pleased to receive them).

As well as publishing and distributing these leaflets, Our

Voice In Our Future is working directly with two local user-led organisations to hold discussions with different groups of service users to get a detailed picture of their views on the future of services and support.

When we have finished meeting and talking to people we will be writing a report that will be used to tell the government and MPs and others who influence policy changes.

There are many points about the future of benefits, welfare and mental health services being debated at present and it's probably worth noting that there has never been very much agreement about the welfare state except in the years after World War Two when the system was being set up.

Our Voice In Our Future is unlikely to break 50 years of disagreement but it can mark the start of a stronger voice for users in this continuing debate.

Our Voice In Our Future is being run by Shaping Our Lives, a national project which works to show the importance of involving users of services in the planning and running of the services that they use. The work is being funded by the Joseph Rowntree Foundation as part of its Shaping Futures programme.

Michael Turner, Project Worker, Shaping Our Lives

1. Changes in the past 20 years

For hundreds of years, in countries like the UK, the response to what are now called 'mental health' issues and problems has mainly been to separate people experiencing madness and distress from others. They have often been subjected to strange and punishing 'treatments'. Such a policy resulted in a history of abuse, including physical, emotional and sexual abuse, and the loss of people's rights and freedom. This segregating approach led to the setting up of the big 'lunatic asylums' which still have a heavy influence on popular ideas of madness and distress today.

There have been many changes in policy and provision for mental health service users over the last 20 years. This has included changes in the way services are organised, the kinds of services available, where they are provided and the workers involved. Over this time, there have been two especially important changes, both of which can be seen as a break from the past. One has come from policy makers and the other from mental health service users themselves.

Care in the community

The first of these changes has been the closure of most of the old big Victorian institutions, the reduction of the number of psychiatric hospital beds and the move instead to what is called 'care in the community' or 'community care'. There are many reasons for this. They include both

positive ones, like concerns about bad conditions and the denial of rights and freedom to service users, and negative ones, like trying to save money on maintaining rundown old buildings and relying on prescribing drugs, frequently associated with damaging effects, to pacify and control people.

The aim of care in the community is that, wherever possible, mental health service users should be able to stay in their own homes or live somewhere nearby and have suitable support to do so. This support would be local or 'community based' and could include support from workers like social workers, community psychiatric nurses (CPNs), occupational therapists (OTs) and so on.

The idea of care in the community was also based on the expansion of a wide range of mental health services 'in the community', including day centres, day hospitals, sheltered and supported housing, access to social housing with visiting support workers, training opportunities, sheltered work and opportunities for 'therapeutic earnings' on top of income from benefits.

Community care, particularly since it was linked with the interest of Conservative governments, which introduced it, in 'consumer choice and involvement', can be seen as a really big new idea. It replaced years of removing people experiencing madness and distress from their homes and locking them up, and talked for the first time about giving them a say in what happened to them.

Unfortunately what seems to have stayed the same is the experience of many service users. They found either that they could not get support, did not have enough support, or did not have the kind of support they wanted. What support you get is also likely to depend on where you live. Most long term users of mental health services still have to live on low incomes. For many, institutionalised life in a

large old psychiatric hospital was only replaced by the isolation and stigma of living in a bedsit on a rundown estate. Existing hospital beds are under pressure and hospitals are frequently an unsafe environment for service users, particularly for women.

Support for mental health service users/survivors to become parents or keep their children has not been forthcoming. Along with parents with learning difficulties, survivors are at much greater risk of having their children removed and put forward for adoption than other parents.

All the signs are that the inadequate funding of care in the community by successive governments ruined the policy. This was made worse by continuing problems of poor communication, coordination and integration between different departments and agencies at both local and national levels.

The mental health service users/survivors movement

The second key development over the last 20 years has been the emergence of the mental health service users/psychiatric system survivors movement. Building on the new opportunities for user involvement offered by community care, people have got organised as mental health service users. A growing number of service users are now involved at local, national and international levels. The mental health user/survivor movement is concerned not only with self-help and mutual support, but also with collective action to improve the service system, campaigning on issues like electroconvulsive 'treatment' (ECT) and to bring about broader changes in attitudes to and understandings of madness and distress.

There are now black and minority ethnic organisations, as well as organisations for people hearing voices, with

eating distress and who self-harm. As well as developing their own organisations, mental health service users have had a growing involvement in and influence on traditional charitable organisations like MIND, and organisations like the Manic Depressive Fellowship have become user-controlled.

Some mental health service users and their organisations have also begun to develop links with the wider disabled people's movement. One example of this is the Common Agenda Project, based at Greater London Action on Disability, supporting and encouraging better understanding, cooperation and joint action between disabled people's and mental health service user groups and organisations.

Twenty years ago, it would have been difficult to believe that a stigmatised group like mental health service users, frequently facing very serious difficulties in their day to day life, would have been able to do so much or have the presence and impact that has now been achieved. It is important to remember this massive achievement, as survivors, when considering the many difficulties and changes currently to be faced.

2. Current provision for mental health service users

Although there is a tendency to focus on mental health services, mental health service users are affected by and rely on a range of policies and provision. The three most important ones are:

- general income maintenance benefits – these include contributory benefits (which people have paid in for); non-contributory benefits (to which you have a right) and means tested benefits (to which you are only entitled if your income and savings fall below a certain level)
- disability benefits to which mental health service users may be seen as eligible if they are judged to be disabled
- mental health policy and provision.

Benefits

Figures suggest that 85% of people 'with mental health problems' don't have jobs. People with mental health problems have the highest rate of unemployment among disabled people. Many mental health service users depend on benefits, which is why it is important not to overlook these. The level of income support is low and people who rely on it live in poverty. The signs are that mental health service users have more difficulty than people with physical or sensory impairments in getting and keeping disability benefits. These 'passport benefits'

are very important since they can raise people's standard of living and quality of life.

However, qualifying for disability benefits may depend on the acceptance of medical explanations of madness and distress. It may also depend on taking or being injected with prescribed drugs which may have damaging and dangerous effects.

A big problem is that policies for benefits don't necessary pull in the same direction as those for services. If the aim of mental health services is to provide support and help people live their lives, a complex and shaming benefits system which leaves people without an adequate or secure income will clearly have the opposite effect and be damaging for people's wellbeing and self-esteem.

Mental health services

In 1991, in its *Health of the Nation* programme, the Conservative government identified national targets for five key health areas where it felt big improvements could be made by 2000. Mental health was one of the areas selected because it was felt that it affected a wide range of the population, young and old, and that improved services could reduce the harm it caused.

In 1998, the New Labour government launched its new plan, *Our Healthier Nation*, to promote health and improve the health and wellbeing of the worst off and least healthy in society and to improve their neighbourhoods. One of its four priority areas was mental health. In 1999, *Saving Lives: Our Healthier Nation* set national targets, aiming to reduce the death rate from suicide and undetermined injury by at least a fifth by 2010.

Two systems currently operate in statutory mental health services. These are:

- care management, mainly provided by local authority social services departments following the National Health Service and Community Care Act 1990
- the care programme approach (CPA) operating under the National Health Service since 1991.

Under the care programme approach, a mental health service user is meant to have their own 'care plan' similar to a local authority 'care package'. They should be involved in drawing up the care plan, be entitled to regular reviews of their plan and they should have a named key worker. Mental health workers have argued that a single system would improve the quality, coordination and continuity of support, and such a simpler system has begun to operate in an growing number of areas.

Multi-disciplinary *community mental health teams* have developed alongside the care programme approach with the aims of increasing the involvement of service users and working in a more holistic and integrated way. Teams can include psychiatrists, psychologists, social workers, nurses, occupational therapists and others. At the same time their differing power, status and values mean that psychiatric approaches and the medical model often still rule. Service users are also concerned about the possible compromise of independence of social workers, particularly in the approved social worker (ASW) role, with its statutory powers for compulsory detention.

The launch of *primary care groups* in April 1999 is also likely to be important for mental health service users. They are also intended to move services away from hospitals to the community. It is too early to know what their effects will be, and whether they will end up as more than just another reorganisation, but so far the participation of service users in them has been limited.

One more very important thing must be said about mental health services. There is a crucial difference between mental health service users and most other groups of social care service users. While the rights of many people may be wrongly restricted by the quality and nature of social care, mental health service users, unlike other disabled people, are subject to legislation and provision which is intended and allowed to restrict their rights and freedom. *By law mental health service users' rights can be removed in the name of 'treatment'*. This puts them in a uniquely disadvantaged position. This issue is now dominating mental health policy and discussion.

3. Issues for black and minority ethnic mental health service users/survivors

The treatment of black people and minority ethnic groups in the psychiatric system mirrors and makes worse the wider discriminations which they face. African Caribbean and African people are over-represented in psychiatric institutions. They are most likely (along with Irish people) to be kept in locked wards, to be given higher doses of potentially hazardous medication than other groups and are more likely than other ethnic groups to be diagnosed with schizophrenia.

African Caribbean people, particularly young men, are more likely to be referred to mental health services by the criminal justice system than by GPs or social services, to be 'treated' with physical rather than talking therapies and admitted to secure services. They are over-represented in special hospitals, medium secure units and prisons. Present evidence suggests that mental health services are not adequately meeting the needs of black and minority ethnic communities because they are not sufficiently sensitive and responsive to the diversity of culture and experience, and that these groups have little confidence in them.

Refugees and asylum seekers are a particularly vulnerable group because of the trauma and loss they have

frequently experienced. Their situation can be expected to worsen as their access to benefits and services is further restricted and media campaigns and aggressive political policies increase the stigma and hostility which they face. Black people and minority ethnic groups are still under-represented in user/survivor groups and organisations. While they have established their own local and national self-help and self-advocacy organisations, these often face particular difficulties securing and maintaining funding.

4. Current plans for mental health services

Many changes are now taking place in mental health policy and practice. Government initiatives include:

- *Partnership in Action – New Opportunities for Joint Working between Health and Social Services* (1998), to improve collaboration and put service users needs first.
- *The National Service Framework* (1999), setting out national standards for mental health as a basis for how money should be spent.
- *Who Decides?* (1999), concerned with key principles for making decisions on behalf of mentally incapacitated adults.
- ‘*Mental Health Czar*’ (2000) established.

But at the heart of all the massive changes which are taking place are *three big concerns* which the government has. These are based on a view of:

- mental health service users as dangerous
- the need to give top priority to ‘public safety’
- achieving this by emphasising control and ‘compulsory treatment’.

This all results from the reaction of politicians and the media to *care in the community*. Many service users and workers thought that community care might be a good idea in principle but that it hadn’t been properly funded or

implemented in practice. For example, two thirds of mental health expenditure in England and Wales still goes to hospital based services although half of the hospitals have closed. Funds saved by the closure of long stay psychiatric hospitals have not been spent on community care but have been used instead in other areas of health care.

However, the tabloid press blamed community care for members of the public being killed by mental health service users. The media/press made a small number of tragic deaths big news, despite the fact that it is much more common for mental health service users to kill themselves or die in questionable circumstances in the psychiatric system. This is now shaping mental health policy, because politicians are anxious to avoid any more scandals and attacks from the media.

While it now looks as though the government intends to keep many aspects of the philosophy and practice of 'care in the community', it also plans radical changes. It wants 'root and branch' reform of the 1983 Mental Health Act. This includes plans to extend compulsory treatment beyond hospital to people living at home through the introduction of 'community treatment orders'. The 1999 consultation document *Managing People with Severe Dangerous Personality Disorder* contains plans to lock up people who have been given this label before they have actually committed any offence.

5. Users' views on proposed changes

It is not yet clear what form government proposals for mental health reform will finally take or what they will actually mean for service users/survivors on a day to day basis. Survivor/service user groups are seriously concerned that both their rights and the quality of support they receive will be at greater risk than they have been for many years. Mental health service users organisations see government plans as unsafe, unsound and unsupportive.

So far they have had little involvement in all these plans for change. While the government requires local health and social services to involve service users in their mental health plans and policies, it has not yet done the same itself. Service users are very worried about the attacks being made on their rights and also the growing stigma they now face. Plans for legal reform look like increasing provisions for control and compulsion, while existing safeguards, which have been seriously inadequate, are being reduced. The fear is that the focus will be on controlling people seen as a danger, rather than on ensuring adequate and appropriate support for the many many more who want it.

Service user groups expect many mental health service users to try and avoid the psychiatric system and 'go underground' rather than risk being compulsorily detained and/or 'treated' by it. Treatment and compulsion are seen as incompatible. Proper rights of appeal and independent advocacy and a right to support, currently lacking in

proposals, are seen as essential. The only ‘treatment’ people may be guaranteed is electroshock (ECT) or neuroleptics (tranquillising drugs) under compulsion. There are fears that proposals for compulsion will discriminate especially against black and minority ethnic people.

There are strong links between poverty, social deprivation and mental health service use. While the government says it is committed to ‘social inclusion’ and highlights the problem of ‘social exclusion’, its current thinking on and plans for mental health policy are likely to make things worse for mental health service users by bringing back old stereotypes of them as unpredictable, strange and threatening.

Mental health service users are also having difficulties with the government’s key policy for combating social exclusion, ‘welfare to work’. The government says it wants there to be ‘work for those who can and support for those who can’t’. The ‘New Deal for Disabled People’, in which many mental health service users are included, is part of this policy. But many mental health service users want a job *and* support.

In practice many mental health service users are finding that this policy means being put under increasing pressure to get off benefits and get a job. This is likely to mean any job – whether or not they can manage full time employment, cope without support, or with the the kind of low grade, low value work that is mostly on offer. Mental health service users are also still less likely to get – and increasingly at risk of losing – the non-means tested, non-contributory disability benefits which can lift them out of poverty and make their life more worthwhile and secure.

6. Users' views on alternatives

Mental health policy and thinking is still dominated by a medical model of madness and distress. Service users and their organisations are increasingly arguing for different ways of understanding and responding to their situation, because the 'treatment' can often be worse than the distress.

A survey of people with mental distress carried out by the Mental Health Foundation found that different things helped different people at different times. Neuroleptic drugs did not work for everyone. They affected different people in different ways, weren't enough on their own and were often provided without information about their unwanted effects. People wanted to have a *holistic* approach to their support which took account of *all* aspects of their life, including the material, emotional and spiritual. They wanted their own expertise about themselves to be valued and to have choices in the treatment they were offered.

The user-led *Strategies for Living* project talked with people with mental distress about the strategies, therapies, supports and activities that they found most helpful. Common themes were:

- acceptance
- shared experience – shared identity
- emotional support – being there. a reason for living

- finding meaning – and purpose
- peace of mind – and relaxation
- taking control – having choices
- security – and safety
- pleasure.

It's not surprising in view of their emphasis on 'acceptance' that mental health service users also report that the way the media stigmatise them, makes them feel worse.

Mental health service users place an emphasis on user-led, non-medicalised alternatives to provide the kind of support they want. These include complementary therapies and personal survival strategies. They have also led survivors to campaign for and develop their own non-medicalised crisis and out of hours services, including safe houses and refuges, help lines staffed by survivors, peer counselling schemes and so on. These are valued by their users, but still only exist on a small scale. They face an uphill struggle to gain credibility and to get funding.

Mental health service users/survivors organisations have also developed their own advance directives and crisis card schemes, so that individuals can specify in advance what they want to happen and who they want contacted when they are having a bad time or don't feel able to take control.

Mental health service users/survivors groups are now paying more attention to attacking the discrimination they face and adopting the kind of rights-based approach to securing support and countering prejudice which the disabled people's movement pioneered.

Mental health service users/survivors organisations are

paying increasing attention to safeguarding their rights and are beginning to make links with the disabled people's movement. They are looking at how they can use the Disability Discrimination Act. One survivor has already won a case under the Act for being wrongfully denied a job.

The new Human Rights Act may also help safeguard service users' rights against plans for compulsory treatment. Many survivors are eligible for 'direct payments' (Community Care (Direct Payments) Act), which put people in control of the support they get. So far very few receive direct payments, but they offer a good way of getting the kind of non-medical support many service users value.

Some mental health service users/survivors are beginning to adopt new forms of collective action, including direct action methods. Groups like *Mad Pride* and *Reclaim Bedlam* are organising demonstrations and lobbies of parliament as a more effective way of getting the kind of change that service users want.

Some service users reject the idea of 'mental illness' as damaging and stigmatic. They are beginning to explore a *social model* of madness and distress. This would challenge the discrimination they experience. It would replace the medicalised individual model of 'mental health' in which service users have to prove mental 'incapacity' to get benefits or support.

Issues for discussion

The following questions may help you to think about the issues about mental health policy and practice. Our Voice In Our Future wants to hear from all service users about their views on these issues. You could send us your answers to these questions or write to us about anything else that you think is important.

Send your comments to:

Our Voice In Our Future, c/o NISW, 5 Tavistock Place, London, WC1H 9SN. Tel: 020 7387 9681. Fax: 020 7387 7968. E-mail sol@nisw2.org.uk

- What are the biggest problems now facing us as mental health service users/survivors?
- How much real say do we have in mental health policy and practice at (a) local and (b) national levels?
- As service users/survivors, how can we get government to act and think more positively about us?
- What are the best ways in which we and our organisations can influence mental health policy and practice?
- Should mental health service users/survivors organisations strengthen their links with the disabled people's movement? What would be the best ways to do this?
- As service users/survivors, which should we spend most time on: developing our own initiatives and plans, or getting involved in the service system to change the ones it has?.

- What do we think about the current emphasis on ‘public safety’ and the dangers from mental health service users?
- What are the strengths and weaknesses for mental health service users/survivors of direct action? Should we be doing more of this?
- What needs to be done to challenge the discrimination mental health service users face?
- What needs to be done to stop the particular discrimination faced by black and minority ethnic communities?
- How is the government’s welfare to work policy working out in our area?
- Are primary care groups making a difference for mental health service users? Is it good or bad?
- What are the implications for mental health service users/survivors of current research into genetic ‘causes’ of madness and distress?
- What particular issues does the psychiatric system raise for women, particularly those with children?
- What supports would parent survivors like to see to enable them to bring up their own children at home?
- What are the implications for mental health service users/survivors of current child care and adoption policies?
- What needs to be done to ensure that more mental health service users/survivors receive direct payments?

Useful statistics

- Official figures suggest that 20% of women and 14% of men in England have some form of 'mental illness'.
- Work related stress is the biggest occupational health problem in the UK after back problems.
- The Labour Force Survey of 1995 reported that users of mental health services have higher rates of unemployment than any other group of disabled people or people with long term physical health problems. Only 21% of people with long term mental health problems are either employed or seeking employment.
- Between them, the NHS and local authorities spend about £6 billion a year on mental health services.
- In 1954 there were about 144,600 psychiatric beds. There are now about 30,000.
- There has been *no* increase in the number of homicides associated with mental health service users since the introduction of care in the community.
- African Caribbean people are twice as likely as white people to be diagnosed with mental illness and three to five times more likely to be diagnosed and admitted to hospital for 'schizophrenia'.
- There are 142,000 hospital admissions each year in England and Wales resulting from self-harm.
- 10,000 people a year still receive ECT in the UK. A third of patients receive ECT compulsorily. A recent audit

showed that only one third of clinics met the standards required by the Royal College of Psychiatrists for administering ECT.

- One fifth of all deaths of young people are by suicide.

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