

MENTAL HEALTH AND SOCIAL EXCLUSION

**A RESPONSE TO THE SOCIAL EXCLUSION UNIT CONSULTATION FROM
THE SAINSBURY CENTRE FOR MENTAL HEALTH**

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**MENTAL HEALTH AND SOCIAL EXCLUSION CONSULTATION
EXERCISE**

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CONSULTATION QUESTIONS

Your views are critical in achieving real change in how services and support are delivered and made available to people with mental health problems. Please complete as many or as few questions as you like.

1. Mental health and social exclusion

Q1 How does mental ill health cause and sustain social exclusion?

Mental ill health is both a trigger for and an effect of social exclusion. It can be causal in the sense that it can begin a process of withdrawal, in both the individual and their social environment, which can be both dramatic in its rapidity and catastrophic in its consequences. People lose their jobs, their work colleagues, their friends and sometimes their marriages. Not infrequently they also start to believe that they deserve all this because of their weakness or because of the mad “shameful” behaviour which they have exhibited when in crisis.

If this process is unchecked all normal adult roles can become unavailable – leaving mental patient as the only career option. None of this is necessary if appropriate practical help and support is provided at an early stage. The process is sustained because mental health services tend to focus exclusively on suppressing the manifestations of the distress/disorder people are experiencing. It is only when these are contained and people are “well” that attention is paid to how people will manage their lives. By then the journey to exclusion will probably have advanced to the point where even the person’s doctors and key workers assume that a life in protected settings without employment is the best that their patients can hope for. Lay people (family members, employers) take their cue from this and thus the prophecy becomes self-fulfilling.

Service users acknowledge that mental health problems can make it difficult for them to relate to others, but it is the reaction of others and not the mental ill health that sustain social exclusion. Deep rooted stigma, discrimination and prejudice compound the problems created by the symptoms of mental health problems for individuals. At a societal level, people with mental health problems experience discrimination at work, in education and in ordinary leisure activities. They also experience the daily risk of harassment, non-acceptance and sometimes violence. Action is needed at all levels if social exclusion is to be tackled.

Q2 What are the 3 most important problems you would like to see the Social Exclusion Unit project address in relation to mental health and social exclusion?

a) At present mental health services do not focus on preventing the journey to exclusion. Many staff lack skills to address the internal factors that create the loss of confidence, competence and hope that are the steps on the journey to social exclusion. It should be a core responsibility of mental health services to address these issues at the earliest stage and throughout the process.

b) There are widely held negative assumptions about the possibility of employment for people with mental ill health and these need to be tackled within employment and education & training settings.

c) Current proposals for reform of the 1983 Mental Health Act miss opportunities to create a climate for increased social inclusion. The Social Exclusion Unit should work with the Department of Health and Home Office to ensure that proposals for reform of the Mental Health Act neither infringe the civil and human rights of people with mental health problems nor increase damaging discrimination by focusing on perceived risk and dangerousness.

2. Employment

Q3 Do you think people with mental health problems want, and feel able, to work? Why/Why not?

There is strong consistent evidence that (when they are asked) the great majority of people with mental health problems would like paid work – either immediately or as a future aspiration. Surveys indicate that even those who have been out of the labour market for a long time still hang on to their dreams and aspirations for work even if they do not want full time employment immediately. Since a specially designed self-assessment process (Employment Workbook) was introduced in Bexley early this year for people on Care Programme Approach who wanted to consider employment, nearly one third of those on CPA have volunteered to join in and more requests are coming in every week.

Q4 What are the main barriers to employment for adults with mental health problems?

The main barriers are in people's heads and can best be described as erroneous belief systems, these include:

- the almost universally held belief that people have to be protected from work until they are completely symptom free – some public services actually have a policy that people with more severe conditions have to have ceased treatment for two years before they can be considered safely employable (even as volunteers according to the Director of HR in one mental health trust)
- that people will need lots of time off work and expensive or disruptive adjustments if they remain employed
- the belief by some psychiatrists that telling people they will never work again (reported regularly by service users) is doing their patients a favour by lowering expectations and encouraging them to be “realistic”
- The belief by some clinical teams that once a person is well enough to work they can be removed from the caseload

This is not to dismiss or take lightly obvious barriers such as how to deal with positive symptoms (voices, periods of mania or depression), the suppressant or embarrassing effects of medication, stigma and bullying in the workplace. However such is the corrosive effect of professional pessimism, both on patients and on the public at large that few people even get to the point of looking at practical ways of overcoming the barriers. They have to develop

and maintain hope and self-belief to look at ways of overcoming these barriers (just like anyone else). This will only happen when the professionals with whom they deal also have belief allied to an optimistic, problem solving approach.

“In the right circumstances almost anyone can work, in the wrong circumstances almost no one will.” Fiona Ford (former senior lecturer in Primary Care studies – University of Liverpool).

Q5 What is the typical experience of adults in work who have mental health problems?

There is no such thing as typical experience. However there are similar problems and dilemmas. A major dilemma is how much (and who) to tell about having a mental health problem. There are risks associated with both disclosure and non-disclosure. If people do not disclose they cannot receive help and often leave things far too late until problems have escalated. On the other hand, disclosure can risk dismissal, damage to promotion opportunities and on a day to day basis having every commonplace issue ascribed to the person's illness. If you are known to have mental health problems you may find it difficult to take time off for a cold.

The experience of some service users is to be trapped in menial work with little job security or to remain in unpaid 'employment training schemes' that do not offer good training or lead to employment.

Peer support in devising disclosure strategies with employers is often helpful. Support to escape from a cycle of low expectation and low paid work is also vital.

Q6 How often do you think adults in work lose their jobs following the onset or relapse of mental health problems, and for what reasons?

In one small survey 80% of people who had jobs on first admission to hospital were unemployed one year later. No one had asked them if they had jobs – much less if they needed help in keeping them. Employers often get rid of people because no one explains to them what is happening in terms they can understand or offers to help them find ways of keeping people on. GPs know that people who are off work consume considerable amounts of their time, but have no training in writing medical reports for employers that help them understand the likely course or duration of the condition. Even if they were to change certification practices and “prescribe” return to work they lack the knowledge, time and resources to help patients negotiate a gradual return to work with their employers.

Posts are often held open for people with lengthy and serious physical health problems, for example having open-heart surgery. However, mental health service users report insidious methods by which employers do not afford them the same treatment. GPs may feel better equipped to help those with physical health problems to negotiate a gradual return to work. In addition, well meaning friends and family may persuade a service user to avoid adverse perceptions of their condition by returning too early to work. This can lead to the possibility of relapse.

So people lose their jobs largely because no one helps them or their employer to keep the post available.

- Q7 What is the best way to help adults with mental health problems find and keep work? Please give details of any examples of good practice or promising approaches.

There is no one single answer to this question because a person with a mental health problem is an individual with any individual's potential or actual range of skills and abilities. However, once people have become unemployed or if they have never worked there is strong evidence that a method called "Individual Placement and Support" is the most effective way of helping them find and keep work. This involves finding a good job match (matching the person's skills to a particular job), rapid placement in the real work situation, a period of assessment and adjustment and then just enough in-work support for both employee and employer - available on a time unlimited basis.

- Q8 How much emphasis do local services place on helping people with mental health problems find and keep work?

This is very variable. A few are trying to find people work as a major objective and then building their services around peoples' working lives. Others have no employment support at all and do not think such services are part of their remit. The latter are in the majority. Where work services do exist they are frequently provided on a small scale by the voluntary sector, are of variable quality and tend to be based on sheltered work rather than competitive paid employment. The challenge is to make employment support services available on a scale that could offer opportunity for all that want it.

Funding problems can pose particular difficulties for voluntary sector employment schemes. Voluntary groups often receive short term funding and have to constantly look for grant renewal rather than concentrating on long-term solutions. Sometimes renewal of financial support is tied to numbers of people for whom work is found rather than on whether the work is suitable and how long an individual remains in any particular post. This can lead to placement but then rapid job loss where work is unsuitable and little support can be provided.

- Q9 How does the welfare benefits system, including the operation of housing benefit, affect people with mental health problems who want to resume work?

The benefits system affects people differently according to their circumstances. However, there are some major problems that always come up when service users talk about employment. Service users tell us that these include:

- An inflexible and unco-ordinated benefits system.
- Poor pay that often means people can fall into the 'benefits/poverty trap'
- Confusion and anxiety about the whole benefits system – including worry that if employment does not work out then claiming again is too stressful.

- Financial arrangements for living in supported accommodation - as it is highly unlikely a service user would be able to earn enough to cover supported accommodation costs.
- A system that is ridiculously unhelpful to anyone working less than 16 hours a week.

Overall, it is impossible for the majority of people on long-term benefits to improve their incomes by working part time (5-16 hours per week), thus preventing them from building up their hours and finding out whether they could tackle full time work. It is impossible for most people living in supported housing to earn enough to pay rent and support costs. However the worst aspect of the system is the perceived level of risk involved in taking on any work at all. The current system makes it possible for people who take on paid work without good advice to be disqualified from disability benefits and put on Jobseeker's Allowance (less money, more requirements, punitive sanctions), thus risking their incomes, their homes and their precarious sanity. There is much work to be done, both technically within the system and in the provision of good independent advice before the majority of people will overcome their perceptions of risk.

Q10 What could the government do differently to enable more people with mental health problems to work?

- Redesign aspects of the benefits system to address the problems summarised at Q. 9 above.
- Require mental health services to keep records on employment rates of service users and also require the local negotiation of joint targets with Jobcentre Plus for year on year improvement.
- Provide training and support for GPs in the management of sickness certification leading to return to work. This is "win-win" because better return to work rates will save GP time and resources at present locked into the unproductive maintenance of chronic conditions.
- Publish the evidence-based guidance on setting up employment services that has already been written and make employment a priority for the NIMHE and the Regional Development Centres.
- A redesign of the Mental Health Act, incorporating aspects of the Scottish Act. Increased inclusion cannot flourish in a climate in which competent people can be compulsorily medicated, and clinicians are watching their backs all the time.

3. Social participation

Q11 Which community-based services, civic and recreational activities are the most important to people with mental health problems? Please give details of any examples of good practice.

Unsurprisingly, service users tell us that they need access to the same range of services and activities as the rest of the population. However, bad experiences of prejudice against them can lead to growing isolation and

coupled with low income this can make people nervous about using ordinary facilities and services. All too often an individual with a mental health problem is contained in a 'mental health ghetto' of services and day care contributing to loss of confidence about integration in the wider community. Self help and peer support can contribute to developing confidence, but this will often be insufficient without active support from mental health services.

There is a wide range of good practice, including examples given in the Sainsbury Centre for Mental Health publication 'Working for Inclusion' (SCMH 2002). This is sent under separate cover for information.

Q12 How easy is it for people with mental health problems to access these services? Why/Why not?

Experience varies but it is often difficult for the reasons given in response to Q1, and is related to issues summarised at Q11 above. Once people have embarked on the journey of mental ill health it becomes very hard to take a first step back into the social, recreational and civic activities that others take for granted.

Q13 How could access to services, civic and recreational activities be improved for people with mental health problems? Please give details of any examples of good practice.

Again there is a wide range of good practice and it may be best to indicate the kind of initiative that can help.

- Public services have been required to address issues of access for people with physical ill health and 'disability' over a long period – the same kind of attention is now required to ensure equity of access for people with mental health problems.
- Mental health services bear a particular responsibility to support individuals to participate in civic and recreational activities. Services must develop a new capacity to work in this way, including day services that are focused on supporting integration and participation.
- As with employment, the issue of leisure and recreation must become part of the Care Programme Approach and be integrated in an individual's care plan.
- Support and advocacy services will need to develop the capacity to help any individual to participate in civic and leisure activities.

Q14 How important are families and friends in supporting people with mental health problems?

This varies. For some the help of family and friends assists people to lead fuller lives. However, others may be shunned by family and friends. Support, education and training of carers is a neglected area with great potential.

Q15 What kinds of attitudes exist in local communities towards adults with mental health problems? Please give details of any examples of good practice in building positive attitudes.

Public fears about the association between schizophrenia and violence (particularly homicide) have been rising in the past decade. High-profile cases such as those of Christopher Clunis and Michael Stone have created a sense of crisis, stoked by a number of mass media and politicians, and led to strident calls for people with severe mental illnesses and personality disorders to be kept 'off the streets'.

Despite the best efforts of numerous anti-stigma campaigns, public attitudes towards the one per cent of people with severe mental illnesses (as opposed to the one-in-four with any kind of mental health problem) are if anything hardening. As a result, local opposition to community mental health facilities remains a major obstacle for health and social services - 'NIMBYism' (not in my back yard). One recent survey found that people with severe mental illnesses who live in their own communities are twice as likely to be the victims of violence as other members of the community.

Positive steps can be taken by national and local government to improve the situation, including:

- Supporting campaigns by voluntary groups to tackle overt prejudice in the media whenever it occurs;
- Government departments and ministers avoiding pejorative language about people with severe mental illnesses;
- Supporting local user groups to shift attitudes in a way that alters people's behaviour. A recent SCMH sponsored study of the service user movement found many groups to be in need of steady financial and practical support to build their capacity to carry out these amongst other functions.

4. Strengthening delivery and measuring results

Q16 How well co-ordinated are services that support people with mental health problems? Are lines of accountability clear?

Stronger links are required between primary, secondary and tertiary/voluntary sector services for people with mental health problems. What is often called a 'whole systems approach' is still not common for health and social care services. Although developments in the NHS Plan are welcomed, they as yet, pay insufficient attention to the need for a co-ordinated approach that tackles the gaps between services. The NHS and Local Government have to take responsibility for increased co-ordination.

However, we need to avoid a single focus on co-ordination internally within the mental health system (and sometimes with the police). Inclusion is a necessary responsibility of mental health services but it will not be sufficient if there is no attempt to join up systemically with employment, education & training, regeneration, urban renewal and other initiatives. Active engagement

to make links with mainstream public services should be a core task of the mental health system at all levels and particularly at grass roots level. Workers need permission and support to build relationships with other agencies; managers need to make this part of their core work. Cross-secondment between Occupational Therapists in community mental health teams and advisers from Jobcentre Plus, which has happened in some places. is an example of a good way of building different kinds of relationship.

Q17 What gaps would you identify in current service provision?

There are many gaps but the Sainsbury Centre would like to highlight two in particular. The first of these is in employment support services. We have addressed this issue in some detail in response to earlier questions.

The second area relates to the education & training of mental health practitioners. Training in socially inclusive practice is very poorly addressed in both pre- and post- qualification training. Few programmes address the issue systematically and academic staff capability is limited. There are, as yet, no validated postgraduate programmes that address social exclusion and mental health practice. The result is that many practitioners have a poor understanding of theory and practice.

The SEU could make this a priority when recommendations are developed. One or two programmes might be established to test out and to stimulate interest in learning about socially inclusive practice.

Q18 Are there examples of good practice in service provision by the voluntary/community sector which could be disseminated more widely?

Q19 Are there examples of good practice in other countries which we could learn from?

We would draw attention to the quarterly journal 'A Life in the Day' (published by Pavilion and now in its seventh year) and 'Working for Inclusion' for examples relating to both questions.

Q20 What would be the best way to measure progress in reducing social exclusion for adults with mental health problems?

There are a number of measures that could be developed, including:

- Systematic measurement of the numbers of people who disclose mental health problems who are in the workforce;
- Increased financial support to service user groups to explore specific problems of access to civic and leisure activities.

5. General

Q21 Is there anything else you would like to tell us?

Even the most severe mental illness is comparatively short lived in its acute form. Mental health services have become better and better at getting and keeping people out of hospital. Services have however made little or no progress in dealing with the most damaging and long lasting consequences of mental illness – the journey to social exclusion and disability.

The journey is not directly related to either the nature or severity of a person's illness. Everyone who acquires a diagnosis of mental illness is at risk of exclusion but for none is it inevitable. As with other people with severe disabilities and impairments, a proportion of people with the most severe forms of mental illness can, by dint of personal resilience and good fortune in the support they receive, lead normal included lives.

Once a person is on the path to exclusion then the longer the period of time outside the mainstream the harder it becomes to get back. However the journey can always be stopped and reversed. It makes sense therefore both in personal and economic terms to intervene early with practical support and assistance. This is particularly important when someone is in employment at the point they become ill. Employment is at the centre of our lives - other parts of our lives are contingent on the income and relationships sustained by employment. Allowing someone to lose a job, just because no one has thought to ask if it can be held open, can ultimately lead to a reckless waste of a life.