Citizenship and Mental Health Policy in Europe

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Abstract

The problems confronted by people who experience mental disorders are often conceptualised in terms of health and illness. However, these problems extend far beyond the healthcare system, into all areas of human life. Having a psychiatric diagnosis may have a negative impact on every aspect of the individual's life, leading to the deprivation or limitation of rights in relation to housing, employment, and family life. In this article, some of these problems are discussed within the theoretical framework of debates on citizenship and on human rights. As the context is Europe, reference is made to the recent policy initiatives with the EU, to national and European level consumer organisations and to cases brought before the European Court of Human Rights.

Introduction

"There is no health without mental health. For *citizens*, mental health is a resource which enables them to realise their intellectual and emotional potential and to find and fulfil their roles in social, school and working life. For *societies*, good mental health of citizens contributes to prosperity, solidarity and social justice. In contrast, mental ill health imposes manifold exists, losses and burdens on citizens and societal systems" [EC 2005: 2].

The positioning of the words 'citizen' and 'society' in a mental health strategy confirms the commitment of the EU to the placement of the mental health agenda within the mainstream discussion on citizenship within Europe. The Green paper, from which these words are drawn, was adopted by the European Commission in October 2005, with a stated priority of improving 'the quality of life of people with mental ill health or disability through social inclusion and the protection of their rights and dignity' [EC 2005: 5(3)].

The concept of citizenship used here incorporates the notion of equal rights for every individual to basic civil, political, social and economic opportunities (Marshall 1973). This also includes the right of every individual to protection from exclusionary laws and social practices which may lead to segregation or discrimination of any kind. It is acknowledged, however, that the existence of laws protecting these rights does not necessarily lead to their implementation, as is evidenced by the fact that many people with mental disorders (and other disabilities) are often prevented from accessing goods and services because of the stigma attached to their condition (Berman and Phillips 2000; Huxley and Thornicroft 2003).

Individuals can, of course, lose these rights by committing a serious crime, the penalty for which is the removal of freedom for a time-limited period. Because of the serious infringement of human and civil rights involved in this deprivation of freedom, there are court hearings to establish the extent of the crime and to come to an agreement on the length of the penalty. However, the same level or protection is not always in place for another group of people - those with diagnosed mental illnesses who do not seek treatment voluntarily. They may be detained for treatment on a compulsory basis, a detention that deprives them of their freedom and excludes them from society, with only minimal safeguards in place. Though the time involved in this deprivation of freedom may vary from days to years, the negative social impact of a period of compulsory detention for psychiatric treatment is long-lasting – hence the need for protection.

Until the 1960s, most people in Western Europe who were diagnosed as mentally ill and in need of treatment, received it in hospital on an involuntary basis. Though countries varied in the admission procedures used, most were based on mental health laws initiated in the nineteenth century. These laws had been enacted with a two-fold purpose – firstly, to protect the individual (with a mental illness) from unnecessary or illegal confinement and secondly, to protect society from dangerous people. However, the emphasis gradually moved to the protection of society rather than of the individual. This led to the growth of large-scale institutions to which admission became easier and discharge difficult. This was not necessarily due to the legal system or to medical opinion, but rather to the fact that once segregated from society on the grounds of mental disorder, people found it extremely difficult to re-enter society. Friends and family were unwilling to trust someone who had been labelled as dangerous or unpredictable.

Italy was one of the first European countries to publicly declare its abhorrence for a mental health care system that led to segregation and social exclusion. Led by Franco Basaglia, a group of psychiatrists and politicians set up *Psichiatria Democratica* and brought about a radical change in the law. The hope was that large institutions would no longer continue to function, and that compulsory admission to much smaller facilities for treatment would only happen after both a judicial and a medical assessment of the situation (Law 180, enacted in 1978; for discussion see Samele 1999). Thus, in one swift action, Italy removed the legal basis and the service structure that had deprived so many people of their civil and human rights. All that remained to do was the implementation of the policy.

In countries other than Italy, the process of legal change has been slow. However, as we begin a new century, the situation in most European countries is promising, with some exceptions among new entrants to the European Union (EU). The majority of people with diagnosed mental illnesses are treated on a voluntary basis (as with other health services) and most of them live at home or in supported housing projects. However, it has to be acknowledged that there is great variation in the services available to people throughout Europe, evidenced by the percentage of health expenditure devoted to mental health services. For example, while Luxembourg, the UK and Sweden devote over 10% of their health expenditure to mental health, the comparative statistic for Slovakia and the Czech Republic is under 3% (EC 2005, Annex 6). While it is not clear how this money is spent, there is some evidence that it may reflect an over-reliance on institutional treatment.

While the size of the problem of mental illness is well documented, it is difficult to estimate the actual level of deprivation or limitation of freedom related to a psychiatric diagnosis. For example, the EU Green Paper on mental health, approved by all member countries in 2005, states that ‘more than 27% of adult Europeans are estimated to experience at least one form of mental ill health during any one year’ (EC 2005, Section 3 and Annex 2). It also states that ‘in the EU, some 58,000 citizens die from suicide every year, more than the annual deaths from road traffic accidents, homicide or HIV/AIDS’ (EC 2005, Section 3 and Annex 3). On the basis of earlier American studies, we can assume that only one out of five of the people experiencing mental health problems will seek treatment and, of these, most will receive this treatment on a voluntary basis (Robins and Regier 1991).

Though conducted some time ago, the review by Reicher-Rossler and Rossler (1993) on involuntary admissions to psychiatric hospitals in Europe, gives us some indication of the need for protection for those who do not seek treatment voluntarily. This review (of hospital admissions in 14 countries) suggests that involuntary (compulsory) admissions formed less than 20% of total admissions. However, there was a wide variation in the statistics, from one per cent in Spain to 50% in Switzerland and Austria. It is also clear that the statistics across countries are not entirely comparable due to different criteria being used to gather statistics. For example, in some countries, mentally ill offenders are counted, while in others they are excluded. However, the statistics do confirm the fact that for a substantial minority of people with mental illness, compulsory treatment in hospital is still a reality – involving the deprivation of liberty and of civil rights (to vote or to enter into a contract). For the majority, however, the mental health care system of most countries provides services to them on a voluntary basis and in the community. The question is – can we assume that the problem has been solved, that mentally ill people are no longer deprived of their basic rights, and that they are living as full citizens in society?

The purpose of this article is to discuss these precise questions, within the context of

- an emerging ‘rights’ movement among service users and professional staff in the mental health services
- the work of the *European Court of Human Rights* (ECtHR) in relation to people with mental illnesses
- the new emphasis on mental health promotion with the EU.

The voice of the service user/expert by experience

The overwhelming message from people with mental illnesses is that they are not functioning as full citizens. Rather, they are often marginalised, stigmatised, and controlled. Their situation is compounded by the fact that there is a higher incidence of diagnosed mental illness among people from disadvantaged sections of society. Thus, we are talking about the poor, the unemployed and the migrant (Middleton and Shaw 1999; Sayce 2001; Thornicroft 1991; Warr 1987). These people are often doubly disadvantaged - by virtue of their socio-economic position and of their mental health problem. Fortunately, there is a growing movement in Europe articulating the concerns of this section of the population. It includes the major NGO *Mental Health Europe,* national and international consumer groups (users of mental health services), groups of mental health professionals and a legal advocacy movement.

There has been a great expansion in recent years in the number and size of self help organisations, including groups initiated by existing or former users of psychiatric services, their relatives and friends – now referred to as ‘experts by experience’. The increase in organisations run by and for service users has been fuelled by a decrease in mental health services and a loss of faith in the medical model of mental health care. It has also coincided with a greater awareness of basic human rights and of citizenship rights by people who had previously taken for granted their exclusion from many social and economic opportunities.

The range of user groups is wide. Older organisations, such as the *Finnish Mental Health Association,* founded in 1897, provide services to support existing mental health services - day centres, housing projects, leisure projects, rehabilitation and education (Ramon 1996). Newer organisations are much more influenced by the civil rights movement, and are involved in promoting individual and group resistance to the status quo. This is carried out largely through advocacy schemes and lobbying tactics aimed at bringing about changes in policies or services. The best example of this comes from the Netherlands where two organisations - the *Client Union and the National Foundation of Patients and Residents Council* have been in existence since the 1970s and facilitate users of services to express their concerns at local and at national level. The Dutch example has been followed by other countries - including Britain and Italy (for further discussion, see Ramon 1996). In Italy, for example, the *Prato* self-help group became very involved in setting up the Italian mental health association *Associazione Italiana Salute Mentale (AISME)*. In the UK, *Survivors Speak Out* provides a forum for service users only, thus empowering people who have lost control of their lives because of their mental illness and of society's response to it. Other organisations are aimed at helping the individual find a solution to and move on from the mental health problem - one of the best know examples of this is the world wide organisation *Alcoholics Anonymous (AA).* Others aim to give support to people who accept their condition as chronic - for example *Rethink* (formerly the *National Schizophrenia Fellowship)* in the UK.

In the past twenty years, many organisations have realised that they have to make an impact at supra-national as well as national level, a realisation that has been enhanced by the growing power of the European Union in matters of law and standards of practice. *Mental Health Europe*, an NGO founded in 1985, as the Regional Council of the Wold Federation for Mental Health, now has 72 member organisations in 30 European countries (MHE 2007). It plays an important role in raising awareness of mental health issues at the highest level of European governance, with participant status in the Council of Europe and working closely with the World Health Organisation Regional Office for Europe. Through this supra-national level instrument, local concerns in relation to the mental health needs can be publicised. The MHE is a member of several advocacy and lobbying groups, including the European Public Health Alliance, The European Disability Forum and the European Women's Lobby (MHE 2005).

The voice of mental health professionals

One can be forgiven for thinking that professional lobbies are often concerned with their own welfare rather than with that of services users. However, in the field of mental health, professionals are increasingly aligning themselves on the side of service users, as it appears that governments may use the mental health services as a dumping ground for people who do not fit easily into society. As mental health law changes throughout the UK, a number of professional organisations, such as the Royal College of Psychiatry and the British Association of Social Workers, are closely monitoring each phase of legal change in order to protect the very vulnerable people to whom the new laws will apply. In addition, there is a new impetus coming from organisations that cross professional boundaries. The *Comite Europeen Droit, Ethique et Psychiatrie (CEDEP)* is an example of the power of mental health professionals interested in promoting human rights in relation to mental illness on a European level. It was founded by Claude Louzoun, a French psychotherapist, in 1989, and has members from nine European countries - Greece, Spain, UK, France, Belgium, the Netherlands, Italy, Switzerland and Germany, and associate members from a further three countries - Poland, Rumania and Russia (Louzoun 1993). The *CEDEP* has made a major contribution to the process of bringing rights issues to the attention of policy makers at

European level, through its conferences, publications and lobbying of European institutions such as the European Commission (see, for example, Louzoun 1990). Though initiated by mental health professionals, the *CEDEP* has representatives from users of mental health services and their families as well as from policy makers at national level, and it is also a member of *Mental Health Europe.*

The major concern of the *CEDEP* during the 1990s has been the need to ensure the protection of the civil and social rights of individuals receiving psychiatric treatment, by building this protection into European legislation. The concern is based on a growing awareness of the fact that, in many countries, the public is becoming increasingly afraid of the potential for dangerous behaviour associated with mental disorder. This fear leads to mental health policies and laws, which are more punitive towards a small proportion of mentally ill people. Of course, the law must protect the rights of this minority, but the majority of patients, who present no risk to society, may be forgotten. Without extra funding, they will continue to receive inadequate care which, in turn, increases the burden not only on the individuals in question but also on other family members.

This is the second major concern of the *CEDEP* – the impact on families of the decrease in psychiatric hospital services without adequate replacement by community services. As in other areas of welfare, the burden of caring for a family member with a chronic mental disorder falls disproportionately on women. As the research literature on disability shows, the effect of this is to limit opportunities for participation in the labour force and general social activities, not only for the person with the mental illness, but also for the carer (for discussion, see Cancian and Oliker 2000). Furthermore, if this family is from a minority ethnic group, it is doubly disadvantaged in terms of access to socio-economic opportunities. It follows, therefore, that women who are carers within a minority population are almost totally excluded from normal social participation and economic opportunities.

The impact of European Court of Human Rights

Although individual nations have a duty to protect the human rights of their citizens, they do not always fulfil this duty equally. When this occurs, individuals can use the *European Court of Human Rights (ECtHR)* to challenge their own government either for non-protection or for infringement of rights. Under the European Convention of Human Rights (European Convention), people with a mental illness, like other citizens can expect to be protected from arbitrary or unnecessary government interference in their lives. The extra component in relation to this group of people is the fact that national governments are obliged to offer special protection to individuals, who are (for whatever reason) not capable of protecting themselves. The directive from the Council of Europe on ‘the legal protection of incapable adults’ makes this point clearly and also clarifies the situation by stating that incapacity may be due to a mental disability - which includes both learning disability and mental illness (CE 1999; see also EC 1996).

In spite of the fact that some of the assumptions which underpin the perspective on mental illness in the European Convention are outmoded (it was drawn up in 1954) progress has been made on the protection of rights. Three of these are discussed briefly here as illustrations of the work of the Court.

The right to medical assessment and review

A number of cases were brought to the *ECtHR*, which clarified the conditions under which a person could be admitted on an involuntary basis to hospital treatment. Three criteria must be met: 1) the existence of a mental disorder; 2) the necessity of hospitalisation as the only solution; 3) the existence of the disorder throughout the complete period of involuntary hospitalisation (see *Winterwerp v. the Netherlands, 1979*). This means that countries have to have medical and legal systems in place for initial assessments and routine reviews of patients in hospital. This latter is very important, as people in the past often stayed in hospital under a legal procedure for involuntary treatment long after this was necessary. This happens less often now, except in the case of offenders (with mental disorders) who are sometimes held indefinitely. This practice was found to be unjust by the *ECtHR*, which ruled that prisoners who had served the 'tariff' period required for the punishment of the specific crime, should be reviewed in the same way as other patients and discharged if not a danger to self or others (for further discussion, see Prior 2001).

For countries such as Italy and Spain, where involuntary patients form a very small proportion of the mentally ill population this specific court ruling may not seem very relevant. However, it is extremely important that the criteria for involuntary hospitalisation be affirmed at European level. This is because some of the countries which have recently become part of the European Union, have underdeveloped mental health services which rely heavily on hospital treatment and treat a large proportion of patients on an involuntary basis.

The right to treatment

As we have seen already, this is one of the main issues being articulated by mentally ill people and their families. Publicly funded services have decreased during the last quarter of the twentieth century and people find access to treatment increasingly difficult. The only cases taken to the *ECtHR* have been in relation to prisoners. The Court clarified that prisoners with mental disorders have a right to adequate and appropriate care and treatment (for example, see *Aerts v. Belgium, 1998; Kudla v. Poland, 2000*; *Romanov v. Russia, 2006*). This is indeed an anomaly, as there has been no such ruling on ordinary patients (who have not been convicted of a crime).

The right to family life

Though there are many areas of family life affected by the mental illness of one of its members, the main issue brought to the attention of the *ECtHR* has been in relation to caring for children (Prior 2003). While the fact that a parent has a mental illness is not sufficient in itself to warrant the removal of children from the home, the state may make the case that the seriousness of the specific mental illness renders the parent unable to care for the child. Thus the removal of the child or children is justified in terms of protection the rights and freedom of others (the children). This can happen to children of any age and can be justified even if the parent who had a mental illness later recovers. In all instances the rights of the children are considered as most important. However, the rights of the parent (with a mental illness) has to be protected insofar as this is possible. For example, when children are temporarily removed from parents who are deemed potentially capable of taking back the care of their children, it is the duty of the local authorities to ensure access and bonding in order to facilitate a future family life together (see *E.P v. Italy*, 1999; *K. and T. v. Finland*, 2000).

In reading through the cases brought to the *ECtHR*, it is clear that this is a very important forum for the clarification of individual rights and the corresponding obligation on governments for the protection of these rights. However, this is a very long drawn out process and individuals who take cases are those who are in contact with organisations which will take an interest in their situation. Many people with mental illnesses are often isolated and do not have this kind of contact. Also, it must be acknowledged that countries with well developed mental health services such as the Scandinavian countries and the Netherlands are ahead of the European Court recommendations. The opposite is true of countries with underdeveloped services – they have to catch up with even the most basic requirements (EC 1999).

The lack of legal support in some countries is being addressed by a legal advocacy movement that is becoming more powerful. A good example of this movement is the international advocacy organisation – *Mental Disability Rights International (MDRI)* – which is based in Washington DC, with projects publicising human rights abuses in a number of countries throughout the world, including Turkey, Estonia, Hungary and Slovakia (MDRI 2005). This organisation draws on the expertise of service users, mental health professionals, and lawyers to advise both governmental and non-governmental organisations on human rights issues in relation to individuals with any kind of mental disability (including mental illness). This highly professional organisation positions itself at the highest possible level in order to influence mental health professionals and policy makers. There is no doubt that their contribution will make a difference at individual and national level in countries which lack publicly funded legal support for human rights cases.

Mental health promotion in the EU

While a number of EU policies were relevant to mental health service users – on disability, housing, employment, human rights – it was only in 2005 that the issues directly concerning this group of people was addressed adequately. The Green Paper: *Improving the mental health of the population*, was accepted by all member states in October of that year (CE 2005). This policy document, which will form the strategic basis for mental health promotion and mental health service provision, is extremely important, as it places this often marginalised group of people at the centre of social and economic development.

The financial implications of not supporting the mental health of the population are outlined clearly in the Green Paper:

“Mental ill health costs the EU an estimated 3%-4% of GDP, mainly through lost productivity. Mental disorders are a leading cause of early retirement and disability pensions. Conduct and behavioural disorders in childhood incur costs for the social, educational as well as criminal and justice systems” (CE 2005, Section 3).

The Green Paper proposes a comprehensive strategy on mental health, acknowledging the role of a wide range of service providers (housing, employment, health) in preventing and responding to different levels of disability and social exclusion caused by mental illness. This policy document is an overdue attempt to co-ordinate initiatives in relation to substance misuse, suicide prevention, children’s health, disability and vulnerability, which already exist but which have lacked co-ordination and co-operation between sectors. By mainstreaming mental health issues and by discussing them in terms of their impact on economic and social development, the Green Paper has already de-stigmatised some of the debate surrounding these issues. Whether or not it will make any difference to the resourcing of services remains to be seen.

The future

The twentieth century saw the growth and the demise of the large institution as the most common response of society to people with mental disorders. As we begin a new century, we see a new classification emerging. There is the minority – people who are seen as presenting a danger primarily to society. These people require either supervision or compulsory treatment in the community or in a secure institution. Then, there is the majority – people who are no threat to society, but who may harm themselves through neglect or poor judgement. These people require support and access to high quality community based services, including drop-in centres, crisis teams, individual counselling, employment and benefit/social security advice and advocacy services. Many of these services fall within a health care structure, but many fall outside of it – for example in employment and housing services. Perhaps, most importantly, all of these people require an acceptance by society into all aspects of life.

Just as is the case with physical health, most of the population will have some experience of mental ill-health at some time in their lives. Whether or not this develops into a serious or a chronic mental illness will depend on the circumstances of the person’s life. As indicated already, there are much higher levels of diagnosed mental illness among individuals from lower socio-economic groups (Middleton and Shaw 1999; Sayce 2001; Thornicroft 1991). In addition, people from certain ethnic backgrounds seem more vulnerable than others to both the experience of mental illness and to hospital treatment (Nazroo 1997; Robins and Regier 1991; Thornicroft 1991). Research has shown that this is attributable to high levels of disadvantage and social exclusion rather than to genetic or other factors.

The experience of mental illness and its treatment is also highly gendered (see Prior 1999). In the past, women appeared more often than men in psychiatric statistics. This was due primarily to the focus in most large scale research on depression, anxiety and neurotic disorders, in which women feature more prominently than men. In recent times however, the situation has changed. As psychiatric beds have decreased and as the focus of attention has changed to one dominated by fear of dangerous behaviour, men are appearing more often than before in psychiatric statistics. Disorders previously excluded from the definition of mental disorder are now being included – for example, drug dependence, alcohol dependence and personality disorder.

What all of this means in terms of the general thrust of the arguments presented here, is that the experience of a mental health problem may be random, but social responses to it are not. Just as is the case with racism, the exclusion of people with mental health problems has become institutionalised and is much more likely to operate if the individuals concerned are poor or unemployed, or from an ethnic minority. The only way to avoid segregation or marginalisation is to ensure funding for a wide range of health, housing and employment services and easy access to the benefit system. If there is a reduction in the level of public funding for community mental health services, then the future will be very bleak. People with money will be able to access good quality services and remain mentally health and socially integrated, while those who rely on the public system (the poor) will become increasingly visible in statistics on suicide, homelessness and crime.

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