

Moving to social integration of people with severe mental illness:  
*from policy to practice*



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## Foreword

After decades of neglect, the issue of mental health is now prominent on the European policy agenda. The recent European Commission 2005 Green Paper *'Improving the mental health of the population - Towards a strategy on mental health for the European Union'* represents an excellent framework for action and will hopefully lead to a new generation of policy reforms across Europe.

The issues that face us could not be more pressing. Mental ill-health in Europe is second only to cardiovascular disease in its toll on morbidity and mortality and accounts for nearly 20% of the total burden of illness. Within mental ill-health, *severe mental illness* poses a considerable burden to society. Its effects on individuals and their families are nothing short of devastating. Severe mental illness reduces life expectancy by between 8-20 years in those affected.

There has been considerable progress in improving the care and lives of people with severe mental illness over the past decade. But we cannot afford complacency. Significant challenges remain before we may state with confidence that the barriers to appropriate care and social inclusion have been removed for persons with severe mental illness across Europe.

It is sobering to list some of these challenges. Ignorance and stigma surrounding severe mental illness remain a significant hurdle. Severe mental illness is too often under-recognised, undetected and under-treated across Europe. National governments dedicate a relatively low share of funds to care for mental health. De-institutionalisation has moved the nexus of care for people with severe mental illness to the community, without investment in community services having necessarily followed. Access to care is often limited. People with severe mental illness and their families are often marginalised from society, and their low socio-economic status compromises their chances of integration and social inclusion further.

The purpose of this report is to provide an up-to-date summary of the status of the issue of severe mental illness today in Europe. Much has been written on this topic in recent years and the intent is not to duplicate efforts. Instead, the report draws from a mixture of policy documents, the published literature and individual interviews with each of us listed below.

We wish to endorse the recommendations and calls to action presented in this report. As advocates, treating professionals, and individuals deeply committed to improving the care options and social integration of persons living with severe mental illness across Europe, we hope that our collective thoughts may contribute to helping advance the situation of persons suffering from severe mental illness across all countries of Europe.

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# Introduction: The state

## 1.1 What do we mean by severe mental illness?

The World Health Organisation (WHO) describes mental health as: “a state of well-being in which the individual realises his or her abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community”. Conversely, mental ill-health includes mental health problems and strain, impaired functioning associated with distress, symptoms, and diagnosable mental disorders, such as schizophrenia and depression (WHO 2001b).

**Severe mental illness is commonly defined as those mental disorders in which psychosis is likely to occur.**

However, no standard definition for severe mental illness exists. Symptoms associated with severe mental illness range in intensity from general unease to abnormal feelings of severe anxiety, coupled with hallucinations or delusions that distort one’s sense of environment and self beyond recognition, causing serious physical health problems and social deprivation (WHO 2001). A commonly used categorisation of severe mental illness includes the schizophrenic and delusional disorders listed under categories F20-29 of the WHO International Classification of Diseases (ICD):

- F20 – Schizophrenia
- F22 – Persistent delusional disorders
- F23 – Acute and transient psychotic disorders
- F24 – Induced delusional disorder
- F25 – Schizoaffective disorders
- F28 – Other non-organic psychotic disorders
- F29 – Unspecified non-organic psychosis

Some broader definitions of severe mental illness have included

- F30.2 – Mania with psychotic symptoms
- F31 – Bipolar affective disorder
- F32.2 and 32.3 – Severe depressive episodes without, or with, psychotic symptoms

(Source: WHO 2003)

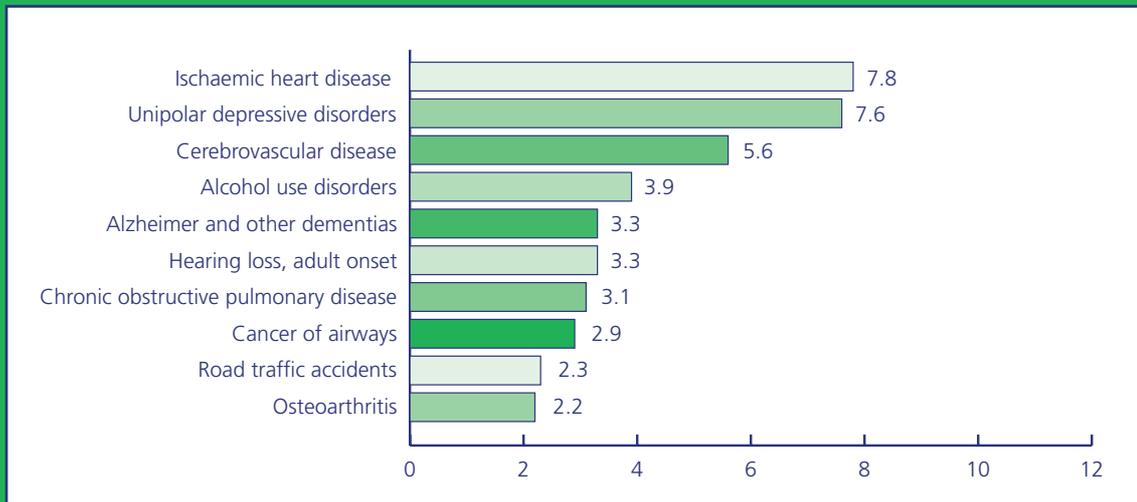
## 1.2 The scale of the problem

Mental ill-health is a severe public health issue in Europe. It is second only to cardiovascular disease in its toll on morbidity and mortality and accounts for nearly 20% of the total burden of ill-health (WHO 2001).

**Yet much of mental ill-health is under-recognised, undetected and untreated** (WHO 2001).

# of the evidence

## Proportion (%) of burden of disease in the European Union in Disability Adjusted Life Years (DALYs), a measure of ill-health and premature death, by cause



Source: IMPHA 2003

Prevalence rates for mental disorders vary significantly between studies and between countries (European Commission 2004). A recent study across 21 countries estimated that the total lifetime prevalence of mental ill-health was close to 50% (Wittchen et al., 2005). This implies that over **80 million women and men of all ages in the EU – one third of EU adults – suffer disorders of the brain** within any 12 month period.

Estimates of prevalence vary considerably from one study to another, mostly due to differences in definitions. For example, the inclusion of wider sub-threshold, but still harmful, bipolar depressive symptoms in some US studies suggests lifetime prevalence rates of bipolar disorders as high as 6.4% (Hirschfeld et al. 2003).

### Estimated prevalence rates for mental illness in the European Union

All disorders of the brain: 80 million people<sup>a</sup>

Psychotic disorders: 1% in any 12 months, equivalent to 3.7m people<sup>b</sup>

Bipolar disorder: 0.8% in any 12 months, equivalent 2.4m people<sup>b</sup>

Hallucinatory or delusional experiences in general population: 10-15%<sup>c</sup>

Schizophrenia, severe delusional disorders as well as other psychotic syndromes (lifetime prevalence): 4.5%<sup>d</sup>

Sources:

a. Wittchen et al., 2005;

b. Green Paper 2005;

c. Johns et al., 2001;

d. Wittchen et al., 2000 and Jacobi et al., 2004.

## 1.3 Severe mental illness leads to poor physical health

The health burden of severe mental illness can reduce life expectancy by between 8-20 years when compared to the general population. People with severe mental illness also suffer an increased risk of being overweight, obese, and having diabetes and hypertension (World Federation for Mental Health & Eli Lilly 2004). **They have a ten times greater risk of cardiovascular disease. In fact, the greatest cause of death amongst persons with schizophrenia is cardiovascular disease** (STAKES 2003).

### Health burden of schizophrenia

Mortality cause (%)	People with schizophrenia	
	Male	Female
Suicides	18	8
Accidents	6	5
Other diseases	13	16
Neoplastic disease	14	19
Respiratory disease	9	10
Digestive system	3	3
Vascular disease	36	38

*Policy makers, insurance companies, health and labour policies, and the public at large do not recognise that physical and mental problems are linked. (WHO 2005c)*

Source: Brown, 1997.

If left untreated, mental ill-health may bring about substance abuse, non-compliance with medicines, diminished immune functioning, and poor prognosis.

## 1.4 Progress in treating severe mental disorders

There has been significant progress in treatment options for different forms of severe mental illness in recent years. The mainstay of treatment is medication. Psychosocial interventions are also now recognised as central to the success of treatment. They can include cognitive behaviour therapy, psychotherapy, family therapy and counselling and community-based services including employment assistance. **Treatment approaches need to be tailored to each individual and adapted on a regular basis.**

Yet a common misconception about severe mental illness, particularly schizophrenia, is that no treatment is available. **Recognition of the importance of choosing the right treatment remains low, even among many treating physicians.** This is compounded by the frequency of non compliance with prescribed medication, shame, self-stigmatisation and a reluctance to 'dare to care' on the part of persons affected by severe mental illness and their families.

*Cost-effective treatments exist for most severe mental disorders. If correctly applied, they may enable many of those affected to become engaged members of society.*

## 1.5 The impact on society

The burden posed by severe mental illness extends well beyond the sphere of health:

- *Quality of life* is severely compromised for people with severe mental illness and their families.
- *Family relationships* suffer significant strain. Informal carers may provide up to 6-9 hours of daily support to people with schizophrenia, for example (McDaid 2005).
- *Limited educational and employment opportunities* may lead to *poverty and stigmatisation*.
- Stigma contributes to *social isolation and social exclusion*. (WHO 2003).

### Staggering economic costs

The social impact of severe mental ill-health translates into staggering economic costs. Data from 15 EU countries suggest that the cost of mental ill-health in general accounts for 3–4% of gross national product (Gabriel & Liimatainen 2000). Indirect costs due to lost productivity and the related burden of care represent up to two-thirds of these costs (McDaid, Knapp & Curren 2005).

Attempts have been made to quantify the costs of severe mental illness (MHEEN 2002). For example, total health care costs for all mental and behavioural disorders in Germany were estimated to be €22.5 billion in 2002, of which schizophrenia and associated disorders accounted for €2.8 billion (McDaid 2005). This does not include lost productivity due to ill-health or care by family members.

EUFAMI estimates that the annual total cost of mental ill-health to society is more than 100 billion Euros in the UK and one trillion Euros for Europe (EUFAMI 2002). Other studies show that mental disorders are associated with total costs of around 290 to 380 billion Euros, estimates which the authors themselves considered conservative (Wittchen et al, 2005).

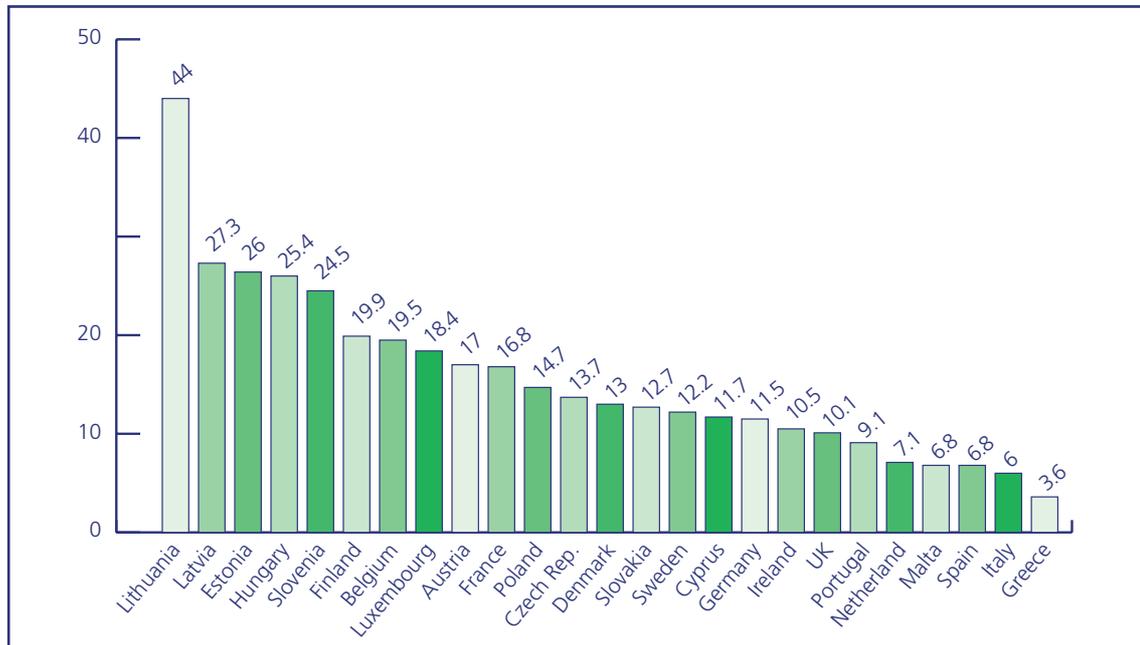
### Premature mortality: the ravage of suicide

Suicide is one of the most alarming risks associated with severe mental illness. **Studies have suggested rates of 10-13% for completed suicides amongst people with schizophrenia** (Caldwell, Gottesman 1990). Risk of suicide is increased with relapse and non-compliance with medication, as well as with concomitant depressive symptoms (J. Rybakowski). **Up to 25-50% of people with bipolar disorder attempt suicide, and 15% are successful (Baldessarini et al. 1999).**

Europe has one of the highest rates of suicide in the world (WHO 2002), with 163,000 suicides in the European Region every year.

There are other factors, of course, which influence suicide rates as well, such as alcohol and drug dependency and socioeconomic deprivation – all of which are associated with severe mental illness.

### Standardised death rate for suicide in the EU-25 per 100,000, 2002.



Source: European Commission 2005.

## 1.6 Risk factors

In many respects, risk factors for severe mental illness are similar to those for mental ill-health in general (see table below).

### Social, economic and environmental determinants of mental ill-health

Risk factors	Protective factors
Access to drugs and alcohol	Empowerment
Displacement	Ethnic minority integration
Isolation and alienation	Positive interpersonal interactions
Lack of education, transport, housing	Social participation
Neighbourhood disorganization	Social responsibility and tolerance
Peer rejection	Social services
Poor social circumstance	Social support and community networks
Poor nutrition	
Poverty	
Racial injustice and discrimination	
Social disadvantage	
Urbanisation	
Violence and delinquency	
War	
Work stress	
Unemployment	

Source: WHO 2004b.

Genetics and gender also play an important role. Schizophrenia tends to appear earlier in life for men, but has more noticeable hallucinations and psychotic symptoms in women. Women with bipolar disorder tend to have a shorter cycle of illness, but they are more likely to require hospitalisation for manic episodes as compared to men (European Commission 2004).

## 1.7 Specific issues with severe mental illness

Many of the issues of concern with severe mental illness are common to all forms of mental ill-health to a varying degree. Nonetheless, **severe mental illness poses specific challenges that warrant particular attention from policymakers.** These include:

- Poor understanding of severe mental illnesses by professionals, patients, carers, policy-makers and the general public
- Increased risk of social exclusion, stigma and barriers to access to effective treatments in many settings
- Considerable discrimination in all facets of community life
- Significant risks of relapse in the case of treatment failure
- The risk of self-harm and suicide with certain exacerbations of disease
- The risk of harm to others with certain exacerbations of disease
- Lack of patient choice and empowerment in care
- Significant human rights issues arising from the practice of enforced hospitalisations.

**By far the biggest challenge we face is the need to combat stigma, discrimination, fear and prejudice and to ensure the social integration of persons with severe mental illness.**

For persons with severe mental illness, integration needs to occur at two fundamental levels:

- as sufferers of a chronic psychiatric condition, through access to appropriate care, treatment and self-empowerment (*integration into the health care system*)
- as vulnerable and marginalised individuals, through access to social services and social acceptance of their equal rights to enjoy full citizenship (*integration into society*).



*Both levels of integration are inter-dependent: access to effective treatment and responsive social services allow individuals to engage within society and lead as fulfilled a life as possible.*

# Mental health policy

## 2.1 The rise of mental health to the EU policy agenda

The last five years have seen a significant increase in the attention given to mental health. The biggest boost to its profile came in 2001, when the WHO chose to devote its *World Health Report* to the topic. Since then, WHO has launched the *WHO Global Action Programme on Mental Health*. In January 2005, the *WHO European Ministerial Conference on Mental Health* set out an action plan and a ministerial declaration on mental health for Europe in collaboration with the Council of Europe and the European Commission.

Recent European policies have made a significant step in moving mental health from the strict confines of the specialist psychiatric domain, to recognising it as a wider societal issue with broad implications for cross-sectoral care, family life, the workplace and the community.

The European Commission has made mental health a top priority on its public health policy agenda. **In October 2005, a Green Paper on Mental Health, entitled 'Improving the mental health of the population – Towards a strategy on mental health for the European Union', was launched** for broad consultation until May 2006. The Green Paper is the culmination of several recent policy initiatives on mental health (see box opposite).



## Momentum for change: European initiatives in mental health

### Mental health as a theme of successive EU presidencies

*Finland (1999)*: focus on mental health, which set the stage for the WHO/Council of Europe Declaration on Mental Health in Helsinki in January 2005

*Belgium (2001)*: Depression, stress-related illness and mental health promotion and prevention

*Greece (2004)*: organised a conference on Mental Illness and Stigma. Adoption by EU Health Council of conclusions on combating stigma and discrimination (EUFAMI 2003b)

### European conferences resulting in Council conclusions:

*1999 – European Conference on Promotion of Mental Health and Social Inclusion* – resulted in a Council resolution on the promotion of mental health

*2001 – Coping with Stress and Depression-Related Problems in Europe*, resulting in joint EU and WHO conclusions on combating stress and depression-related problems

*2002 – Future Mental Health Challenges in Europe: Strengthening Cooperation between EU and WHO*

*2003 – Mental Illness and Stigma in Europe: Facing up to the Challenges of Social Inclusion and Equity*, WHO and Council of Europe Council conclusions on combating stigma and discrimination in relation to mental health

### The European Commission working party on mental health

Set up as part of the Community Action in the field of Public Health 2003-2008. Major activities include:

- *Implementing Mental Health Promotion Action (IMPHA) Network*: run across 28 countries, it developed a European Action Plan 'Mental Health Promotion and Mental Disorder Prevention' in 2004. (IMPHA 2005)
- The *Health Monitoring Programme*: collection of indicators for mental health across different countries (STAKES 2003)
- The *Mental Health Economic Evaluation Network* initiative: collects data and offers best practice recommendations as to funding, utilisation of resources, links between employment and mental health, and other economic issues (MHEEN 2005).

### European Parliament Resolutions:

On 24 June 2005, the European Parliamentary Assembly adopted Resolution 1460 on '*Improving the response to mental health needs in Europe*'.

Adapted from Green Paper 2005.

## 2.2 Priority areas for action

EU policy themes echo those of the WHO. Policy documents call for **social integration, reduction of stigma, and community-based treatment which may provide support and help patients and their families integrate into wider society** (European Commission 2004).

Given the limited mandate of the EU in terms of health care system organisation and financing, many EU policy documents call upon member states to develop national mental health policies. Priority areas for action are to:

- Deliver **high quality and accessible care and treatment services**, accessible to all those with mental ill-health (European Commission 2005).
- **Tackle stigma and discrimination:** The EU calls for the public, social partners, public authorities and governments to:
  - change attitudes themselves
  - encourage public awareness of the necessity of integrating mentally ill and disabled people into working life (McDaid and Thornicroft 2005)
- **Create a better information base** to help justify service improvement and expansion based on solid evidence on:
  - the clinical and cost-effectiveness of interventions for prevention, treatment and rehabilitation of mental conditions. (McDaid and Thornicroft 2005)
  - the economic case for greater investment in mental health services (McDaid and Thornicroft 2005).
- **Protect funds for mental health:** earmarking budgets and creating direct payments to service users (i.e. patients and carers) may ensure that adequate resources are available to meet need. (McDaid and Thornicroft 2005).
- **Prevent suicide**, through:
  - A better evidence base on risk factors
  - Initiatives that encourage those at high risk to seek help
  - Better training for health and social workers to recognize risk factors earlier (WHO 2001).
- **Continue the process of de-institutionalisation:** A switch of services to primary care, community centres and general hospitals can support social inclusion, whereas continued use of large long-stay hospitals can easily reinforce stigma.
- **Empower patients and their families: greater engagement of persons** affected by severe mental illness and their families in all aspects of their care (European Commission 2005).
- **Target vulnerable groups**, recognising the links between social deprivation and mental ill-health.
- **Promote prevention and recognition of risk factors** through dedicated public health initiatives.

## 2.3 The legal framework

The legal framework for severe mental illness in any given EU Member state has two broad foundations. As Member states retain competence in the field of healthcare, direct legislation concerning service provision and patient rights must originate in national parliaments. However, all EU members are signatories to a backdrop of existing human rights commitments established by international treaties. Key treaties and directives include:

### The European Convention on Human Rights (ECHR) (1950)

#### The United Nations

- The United Nations Universal Declaration on Human Rights
- Principles for the protection of persons with mental illness and the improvement of mental health care (General Assembly Resolution 46/11 1991)
- Declaration on the Rights of Disabled Persons / The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1992)

#### The European Union

- The Maastricht Treaty (1993)
- The Treaty of Amsterdam (1999)
- The European Charter of Fundamental Rights (2000)

Individuals may use these treaties as a basis to challenge national legislation and practices if they can prove that they compromise human rights.

The *European Convention on Human Rights* has been incorporated into national law across the EU and allows alleged violations to be presented to the European Court of Human Rights in Strasbourg (EUFAMI 2003). The UN 1991 directive and 1992 declaration both established the right to participation by patients and carers in service delivery. The European Union treaty of 1993 integrated human rights into the legal order of EU law, a process reinforced by the Amsterdam Treaty (1999) (EUFAMI 2003). Individuals can bring cases to the European Court of Justice (ECJ) in Luxembourg.

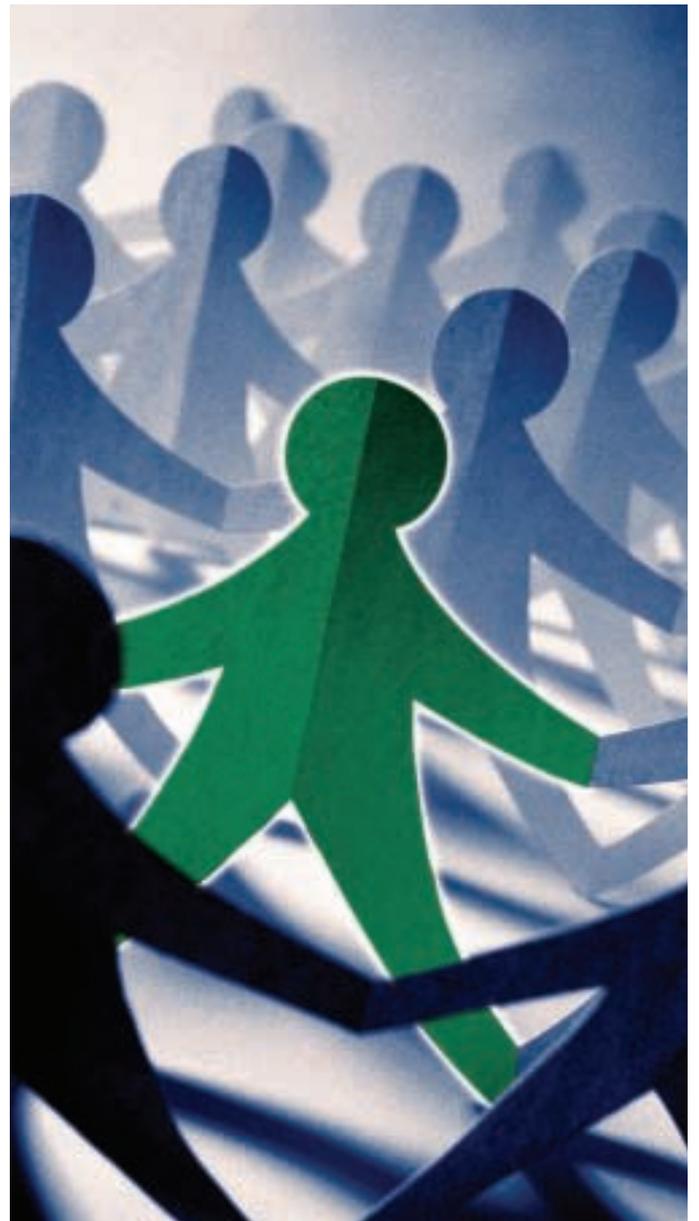
The *European Charter of Fundamental Rights* largely brings external pre-existing treaties into the realm of EU guidance, primarily from the UN and the European Convention. **Currently, the Charter is not legally binding within member states** but remains a strong influence on ECJ rulings and national legal frameworks governing mental health. Experts anticipate that the Charter will eventually become law across the EU (EUFAMI 2003).

# Making it local: build

## 3.1 The importance of national policies

Europe has provided a strong push for mental health policies, but implementation of policy goals is patchy across Europe. According to the WHO Mental Health Atlas, ten out of the 25 EU member states have yet to implement a comprehensive national policy on mental health (WHO 2005b).

National policies on mental health are vital if we wish to address the health and social needs of persons with severe mental illness. **First and foremost, policies are needed to reverse the massive gap in public spending on mental health relative to the burden of other conditions.**



# ing the foundations

## Status of national mental health policies, programmes and legislation.

Country	Mental Health policy (initiated or most recently updated)	National Mental health programme	Status of National Mental Health Legislation (last updated)
Austria	Yes (1999)	Devolved to regions	No comprehensive
Belgium	Yes (1990)	Yes (1990)	Devolved to regions (2000)
Cyprus	Yes (1985)	Yes (1995)	Comprehensive - Mental Health Act (1997)
Czech Rep	Yes (2001)	Yes	No comprehensive
Denmark	Yes (1991)	Yes (1997)	Comprehensive - Mental Health Act (2002)
Estonia	Yes (2002)	No	Comprehensive - Mental Health Act (1997)
Finland	Yes (1993)	Yes (1999)	Comprehensive - Mental Health Act (1990)
France	Yes (1992)	Yes (1985)	(Under review)
Germany	Yes (2002)	Devolved to regions	Devolved to regions (1999)
Greece	Yes (2001)	Yes (1984)	Comprehensive - Mental Health Act (1999)
Hungary	No (under development)	Yes (2001)	General healthcare legislation (2001)
Ireland	Yes (under review)	No	Comprehensive - Mental Health Act (2001)
Italy	Yes (1994)	Yes (1999)	Devolved to regions (1998)
Latvia	Yes (2004)	Yes (2004)	No comprehensive
Lithuania	Yes (1993)	Yes (1999)	Comprehensive - Mental Health Act (1995)
Luxemb.	Yes (1991)	Yes (1991)	(Under review)*
Malta	Yes (1994)	Yes	(Under review)
Netherlands	Yes (1999)	Yes (1999)	General healthcare legislation (1994)
Poland	Yes (1995)	Yes (1995)	Comprehensive - Mental Health Act (1994)
Portugal	Yes (1995)	Yes (1996)	Comprehensive - Mental Health Act (1998)
Slovakia	No	No (under development)	General healthcare legislation (2004)
Slovenia	No	No	(Under review)
Spain	Yes (1985)	Devolved to regions	Devolved to regions (2000)
Sweden	No	No	General healthcare legislation
UK	Yes (1998)	Yes (1999)	Comprehensive - Mental Health Act (1983)

Derived from WHO Mental Health Atlas 2005

\* Prof. Rossler, personal communication

The need for comprehensive mental health policies is particularly acute in countries of Eastern and Central Europe, where institutionalisation was still common practice until very recently. Health and social care systems are still in a state of transition and mental ill-health is highly stigmatised.

*Many of the countries that have adopted national mental health policies and plans have shown a demonstrable impact on mental health outcomes as measured by key indicators<sup>1</sup>.*

## 3.2 Finding a home for severe mental illness within current policy debates

Awareness of the burden of mental ill-health varies significantly from one country to another. One of the key challenges with severe mental illness is to know where to 'place' it within overarching debates about the future of health and social care, user empowerment, social inclusion and discrimination.

**Some countries consider mental ill-health (and hence severe mental illness) as a disability, whereas others treat it as a chronic disease within policy frameworks.** At the EU level, mental health was admitted within the *Disability Forum* in the EU Parliament in 2002. Yet how severe mental illness fits into the current Anti-discrimination legislation may also vary at individual country level.

## 3.3 Building information and surveillance

Solid information on the epidemiology, risk factors, treatment patterns and outcomes for persons with severe mental illness is needed for policies to be evidence-based. Registries on mental illness may be set up within hospitals or across networks of professionals to collect systematic information over time that may enable service improvements.

*Finding the right platform to engage policymakers on the topic of severe mental illness is essential to ensure that clear scope and direction are given to national policies and actions.*

<sup>1</sup>Sources include: Kemp, 1994; Cohen & Natella, 1995; De Jong, 1996; Commonwealth Department of Health and Family Services, Australia, 1997; Thornicroft & Tansella, 1999.

## 3.4 Engaging key stakeholders

**There are four key groups of stakeholders who need to be engaged in the development of severe mental illness policy: persons with severe mental illness, families, professionals, and policy-makers.**

The respective role and power of these different groups differs from one country to another. Some political climates are less or more encouraging than others in engaging patient or user representatives in policy and service planning. Family and patient groups are not always viewed as a useful resource for professionals. They suffer from chronic shortage of funds.

Typically, advocacy and support groups are just emerging in countries of Central and Eastern Europe or the Baltics, where there is less of a tradition of advocacy and lobbying. This is in sharp contrast to the situation in many Northern European countries, where they are a recognised partner in policy discussions.

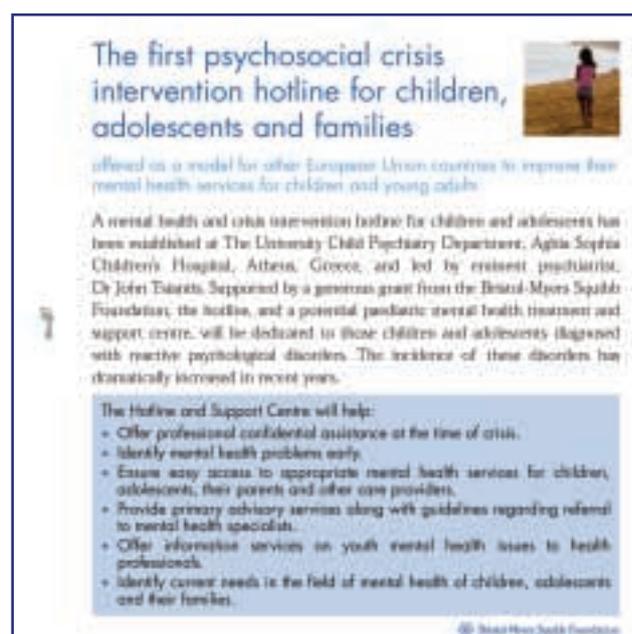
Professionals are not limited to treating physicians in the community and hospital psychiatrists. They include nurses, social workers and psychologists involved in providing care. Professionals working in social services, sheltered housing and community centres are critical also in enabling the social integration of persons in society.

## 3.5 The role of families and carers

Families play an essential role in advocacy and lobbying, raising awareness, coordinating care and fighting for the rights and needs of persons with severe mental illness. They play a critical role in enabling more user involvement in care decisions. Involvement of families has been shown to enhance the quality of life of persons with severe mental illness (Mangan 1994) and reduce the risk of relapse (Ostman et al. 2000). At the same time, better availability of services in the community may lessen the burden on carers.

Complex issues arise from the family dynamics of persons with severe mental illness. For example, in many countries little regard is given to the support of children by mental and social services who may be providing considerable care for parents with severe mental illness (*I. Tsiantis*). The European Parliament has recently adopted a Written Declaration on Child Helplines in Europe. This Declaration recognised child hotlines as an essential part of the child protection system (European Parliament 2006).

### A psychosocial crisis intervention hotline for children and youth established in Greece



**The first psychosocial crisis intervention hotline for children, adolescents and families**

offered as a model for other European Union countries to improve their mental health services for children and young adults

A mental health and crisis intervention hotline for children and adolescents has been established at The University Child Psychiatry Department, Agia Sophia Children's Hospital, Athens, Greece, and led by eminent psychiatrist, Dr Jofel Tsantis. Supported by a generous grant from the Beata-Majors Szalkai Foundation, the hotline, and a potential psychiatric mental health treatment and support centre, will be dedicated to those children and adolescents (diagnosed with reactive psychological disorders). The incidence of these disorders has dramatically increased in recent years.

**The Hotline and Support Centre will help:**

- Offer professional confidential guidance at the time of crisis.
- Identify mental health problems early.
- Ensure easy access to appropriate mental health services for children, adolescents, their parents and other care providers.
- Provide primary advisory services along with guidelines regarding referral to mental health specialists.
- Offer information services on youth mental health issues to health professionals.
- Identify current needs in the field of mental health of children, adolescents and their families.

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## 3.6 Adopting the ‘Dare to care’ principle

The ‘Dare to care’ principle was launched by the WHO in their 2001 campaign ‘Stop exclusion. Dare to care’. It seeks to empower persons with mental ill-health or disability and their families, to teach them to care for themselves, to seek treatment proactively and early in the course of disease.

**Experience may be learned from anti-discrimination campaigns for other marginalised groups, such as ethnic minorities and people with disabilities, to enable individuals and their families to ‘dare to care’ and to ensure that barriers to engagement are removed.**

### Tackling stigma around severe mental illness at an early age



In Denmark, the Danish Mental Health Fund launched the ‘Happy Bus’, which provides full educational facilities, including internet access, within a mobile unit that goes around the community and targets children and young adults.

In Malta, a series of children’s books was launched with the endorsement of the Ministry to educate children about mental illness. Stories and accompanying drawings were devised by the mother of a child with schizophrenia. They told the story of how it was to have someone in one’s family (a parent, a sibling) with mental illness. The books were broadly distributed in schools (*I. Nilsson, EUFAMI*).

## 3.7 Establishing local ‘pacemakers’

A necessary step towards building sustainable policies on severe mental illness is the establishment of an independent, highly credible advocate whose voice may be a constant at every stage of policy development and service transition. This role is typically played by advocacy groups and sometimes by professional network organisations.

What is needed is a ‘pace maker’ which continuously engages the media and policymakers beyond the initial enthusiasm of dedicated campaigns. The establishment of such an organisation is critical to ensure that policy goals are applied and that investment and commitment to programmes is sustained over time.

### Education and promotion in Denmark

**One of the best ways to combat stigma is by increasing understanding of severe mental illness.** The Danish Mental Health Fund, for example, uses a variety of tools to inform the general public, patients and their families, professionals and politicians about mental ill-health:

- A dedicated membership magazine, *Psykiatri-Information*, which is distributed to 40,000 subscribers. It includes research updates, highlights new treatments, and provides information about local and regional activities.
- Books on selected psychiatric and psychological topics
- Public meetings aimed at the general public and the media
- 1- and 2-day courses on selected topics, eg. Self-esteem, cognitive psychotherapy.

(Source: Gerlach and Budde-Lund, 2004).



# Social integration:

## 4.1 Social and cultural factors

### Stigma and discrimination

Stigma, bred by ignorance and discrimination, is a significant hurdle to social inclusion of persons with severe mental illness across all societies. **Beyond social isolation, stigmatisation can cause families to delay health-seeking behaviour, thus compromising outcomes.**

Stigmatisation may sometimes be more socially inhibiting than the disease itself, leading to low self-esteem, social isolation and non-compliance with medication (Gerlach and Budde-Lund 2004).

**In theory, de-institutionalisation promotes social inclusion, but this is only true if society is ready to accept people with severe mental illness as equal citizens within their communities.**

**It is important to acknowledge that stigma is not only rife within society, it is also present amongst persons with severe mental illness and their families themselves, as well as professionals** (Lauber et al. 2004). One example cited in Lithuania was that pharmacists were found to be dispensing medication to patients with severe mental illness that was past its expiry date (*R. Elgie*).

#### Anti-stigmatisation campaigns

EUFAMI, the European Federation of Associations of Families with Mental Illness, has led an active anti-stigma campaign entitled 'zerostigma'. This campaign has been adapted by many countries. For example this year, Poland launched the '4th Day of Solidarity with People with Schizophrenia'. They also launched a campaign 'Against Stigma for Schizophrenia: Open the Doors'.

The logo for 'zerostigma' features the word 'zero' in a bold, black, sans-serif font, followed by 'stigma' in a lighter, grey, sans-serif font. The 'o' in 'zero' is a solid red circle.

### Everyone is fine until a tragedy occurs

**An important factor contributing to the marginalisation of people with severe mental illness is the fear that they will commit violent crimes.**

*'Tolerance of so-called craziness has not increased in the general population. Everyone is fine until a tragedy occurs'.*

(P. Bovet)

# levers and barriers

## Tacking stigma head-on: the example of Sweden

Possibly the best way to tackle stigma is to address it head-on at a governmental level. A successful example of this is from Sweden. A few years ago, two tragic, highly-publicised killings by persons with schizophrenia, prompted a debate over the role of psychiatry in Sweden. The government appointed Anders Milton, former head of the Red Cross, to head a new National Psychiatric Services Coordination taskgroup (the *Nationell Psykiatrisamordning*) and look at 2 questions: whether de-institutionalisation had led to a rise in violence in Sweden, what the responsibility of the mental health services was to reduce the risk of violence.

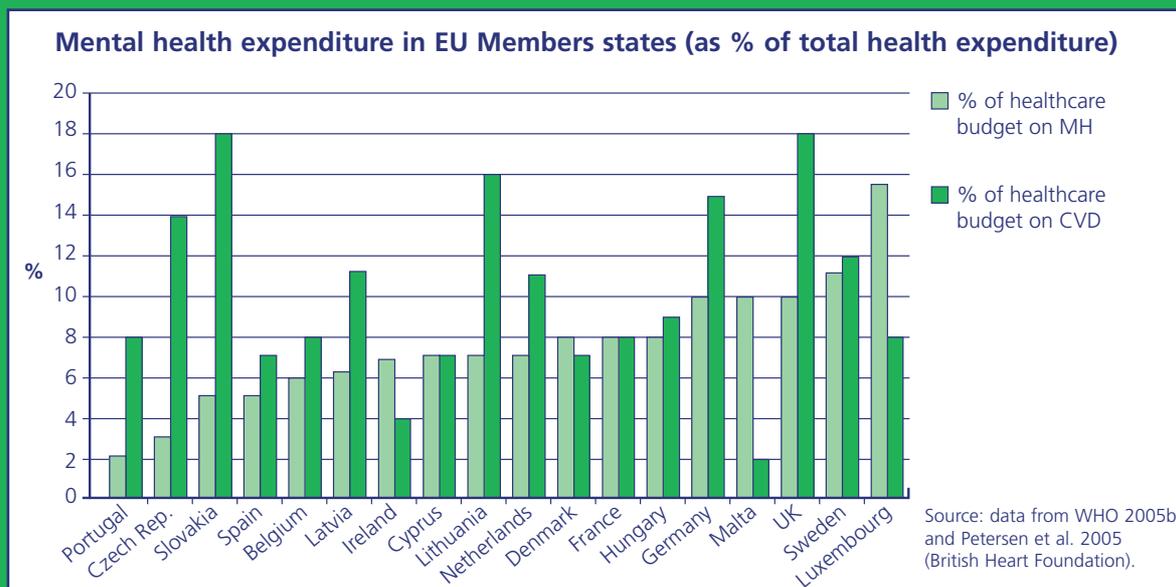
Although there were evident risks in giving this issue such centre stage, the fact that it was being addressed in a formal, government-sponsored manner had overall positive effects. The Milton Commission forced a difficult but productive debate about the most ethical approach to take towards persons with severe mental illness. Its recommendations led to the creation of avenues for more direct involvement of carers and users in policy-making for mental health. The Commission is also exploring innovative partnerships between local government, carer and user groups, county councils, employment offices and other public bodies to improve opportunities for people with severe mental illness in the community.

## 4.2 Funding and resourcing services

### Pervasive under-funding

Investment in mental health is low in terms of personnel and resources relative to other healthcare services (McDaid et al. 2005). Levels of funding vary significantly across countries, but remain grossly insufficient to meet current demand. Six EU countries have **no** dedicated funding allocated to mental health: Austria, Estonia, Greece, Poland, Slovenia and Slovakia (WHO 2005b).

Discrepancies in levels of funding reflect, up to a certain extent, national expenditure on health, which ranges from 5.5% of GDP in Estonia to 10.8% in Germany (WHO 2005b). Yet an analysis of the proportion of health expenditure spent on mental health as compared to cardiovascular disease reveals large inconsistencies across Europe – which bear no relation to the relative burden posed by these conditions.

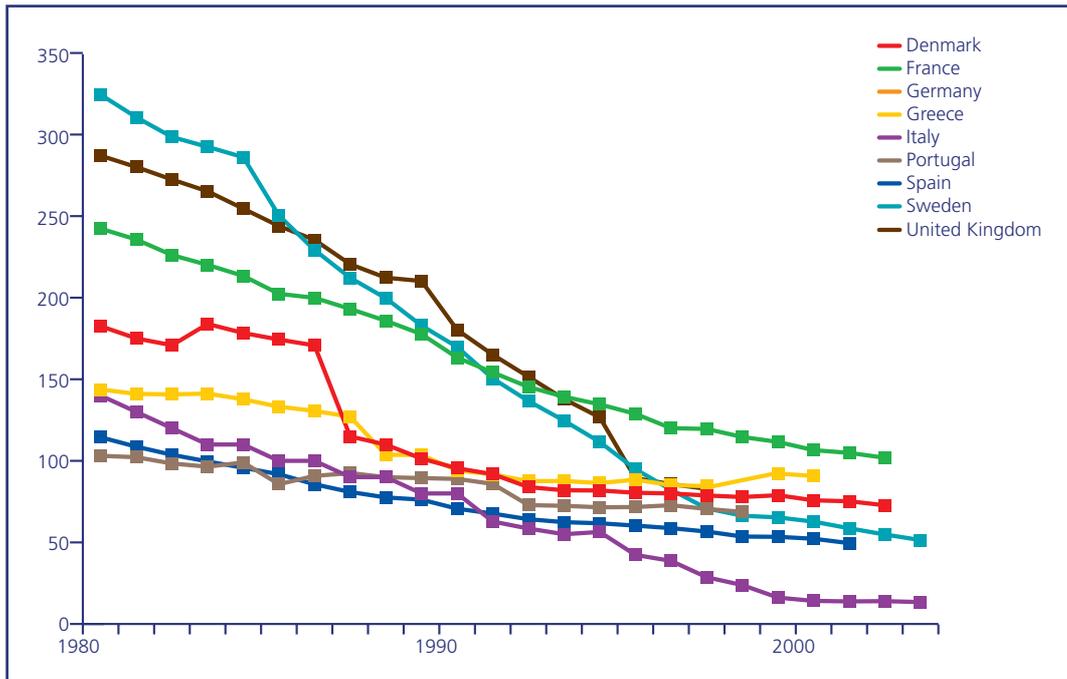


**A contributing factor to low funding is that many support services for persons with severe mental illness are provided outside the health sector (McDaid et al. 2005). Planning for mental health services is most often piecemeal and inadequate.**

## De-institutionalisation and the shift to community care

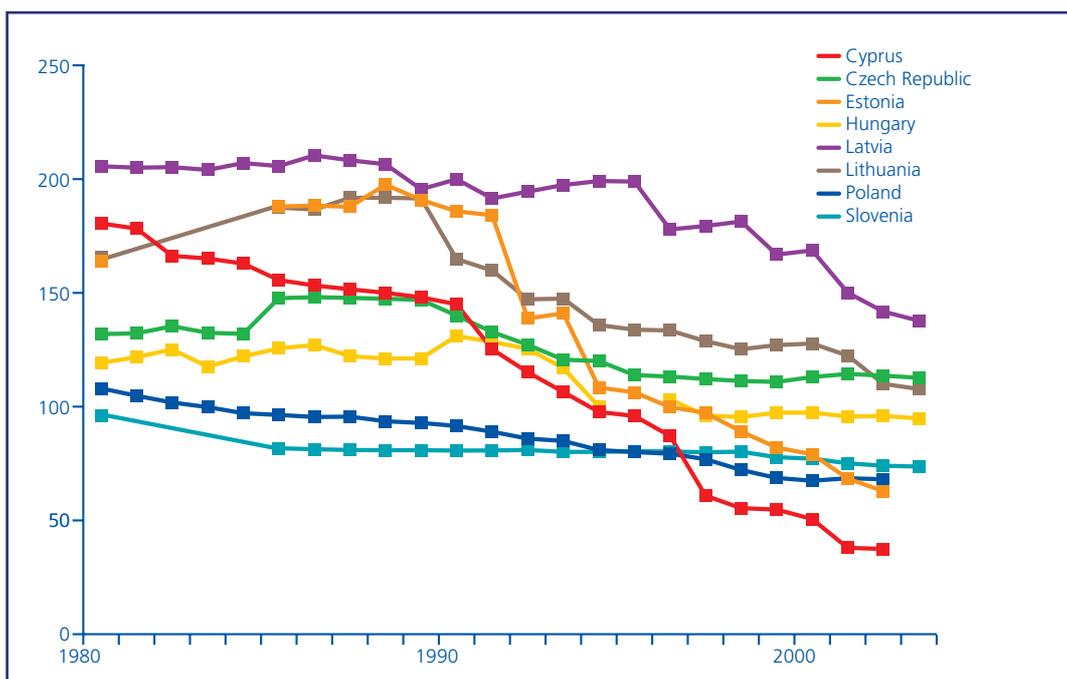
Over the past two decades, governments across Europe closed large numbers of psychiatric institutions and hospitals to move the focus of psychiatric care into the community. Sweden, for example, closed 70% of its psychiatric hospital beds in the 1990s. The total number of beds dropped from **27,000 in 1980** to around **5,500 in 2000** (Health for All Database 2005).

### Psychiatric hospital beds per 100,000 – selected EU-15 countries, 1980-2003



Source: HFA 2006

### Psychiatric hospital beds per 100,000 – selected EU-10 countries, 1980-2003



Source: HFA 2006

The shift of care to the community has not been without its problems. **Too often, de-institutionalisation was seen as an easy way to reduce mental health budgets, and it was not matched by sufficient investment in community services.** Primary care services have not been adapted to meet the needs of patients with severe mental illness. Also, the maintenance of sufficient numbers of beds for the short-term treatment of patients presenting with psychotic episodes has not always been ensured.

Thus severe gaps in care exist in several EU countries (WHO 2005b).

These gaps in treatment have considerable externalities such as poverty, homelessness, social exclusion, violence and contact with the criminal-justice system for persons with severe mental illness. These challenges are greatest where social service provision is dire, namely in Central and Eastern Europe (McDaid and Thornicroft, 2005).

### Is the community capable of caring?

**De-institutionalisation has shifted the burden of care onto communities, without ensuring that communities have the capability to care. There is a shortage of community services across all countries.** Available services often have limited hours of operation. Huge regional inequities exist both in access and quality of services. Funding comes mostly from the private or voluntary sector, with little sustained public funding.

**What appears to be lacking most across a number of countries are facilities that bridge between social and health care.** The demand for places in community centres, day shelters, and sheltered accommodation almost always exceeds supply.

Successful community care also requires good communication between healthcare professionals and carers. Yet laws protecting patient confidentiality may be an unforeseen obstacle, as they may forbid a psychiatrist from advising family members of a patient's change in medication without the formal consent from the patient. As a result, family members may not be fully aware of the possible side-effects of treatment or be able to best interpret the patient's behaviour and take appropriate actions. **As ever, the appropriate balance between patient confidentiality and family needs for information must be found.**

### Lack of sheltered housing: forced isolation

Sheltered accommodation may play a key role in facilitating social integration of persons with severe mental illness into the community. Sheltered homes, for example, may provide a suitable family-style setting to welcome individuals and offer them progressive independence.

In the absence of sheltered housing, patients are relegated to hospitals or long-term psychiatric institutions. In hospitals, they use up beds usually reserved for acute care. Standards of care tend to be low. Long-term psychiatric homes are often isolated from city centres and residential communities. **If a patient is sent to such a facility, he is effectively isolated from his family and his community – not only by his illness but by geographic isolation.**

## 4.3 Organisation of care

### Lack of accountability

**With de-institutionalisation, a key factor is who takes responsibility and is accountable for the overall outcomes of persons with severe mental illness.**

In the old model of psychiatric care, the hospital-based psychiatrist was the patient's main point of contact – if indeed he sought care at all. Today, this role falls upon GPs and/or office-based psychiatrists. Community-based physicians are thus expected to orient individuals towards the complex web of social support and services in the community. They are also expected to monitor compliance and prevent relapse. **Sadly, most of these professionals lack the skills, knowledge and time to fully play out this role.**

*There is, within the community, no obvious patient advocate – that responsibility rests more and more with carers. Yet with changing family patterns and the ageing of the population, we cannot take it for granted that the same level of informal care will be available indefinitely.*

Compounded with the problems of de-institutionalisation are those of decentralisation. Health reforms often affect health and social care structures separately, often leaving a gap in coordination and provision.

'In Poland, there used to be 49 regions, which each had their own administration and provided a web of outpatient services within each region. In 1999, the number of regions was reduced to 16, as part of the reform of health care and insurance. However, the organisation of mental health care was not sufficiently realigned with these changes. Most outpatient services are now privatised and working for profit. Community projects essentially vanished. Since the reforms, we have actually seen an increase in hospital admissions. Patients sometimes have difficulties to access out-patient care'.

(J. Rybakowski)

## 4.4 Professional issues

### Inadequate training

Inadequate training of psychiatrists, primary care physicians and nurses in community and hospital settings is a problem across several countries. For example, regular training for primary care staff in mental health issues does not take place in Denmark, Germany, Greece, Slovakia, Spain or Sweden (WHO 2005b). These training deficits apply equally to other health and social care workers, such as social workers, psychologists and community psychiatric nurses.

### Time and resource pressures on community physicians

Compared to other diseases, severe mental illnesses can be resource intensive to diagnose, treat and manage in a community setting. Community-based physicians who are under pressure for time and resources might thus be reluctant to take on new patients with severe mental illness. Fear of misdiagnosis may incite them to refer patients to hospital-based specialists unnecessarily, thereby delaying essential treatment.

### Hospital-based psychiatry: high turnover and low staff morale

Understaffing by psychiatrists, nurses and psychologists is chronic in many psychiatric wards. Keeping a psychiatric unit going has been described as a 'daily challenge' (*l. Bitter*). Wards are in chronic deficit and staff desertion to seek better-paid jobs in other EU countries is a growing concern in many of the newer EU states.

### Treating the whole patient

Patients with severe mental illness have complex medical needs that extend beyond the pure psychiatric domain.

*'To treat severe mental illness effectively, one needs to deal with both the psychiatric as well as the somatic effects of illness. A holistic approach to treatment and care is needed for the best outcomes to be achieved.'*

(U. Osby)

Yet this 'holistic' treatment of the patient may have been lost with de-institutionalisation. Non-psychiatric symptoms may often go unobserved and untreated.

#### De-institutionalisation: compromising patient outcomes?

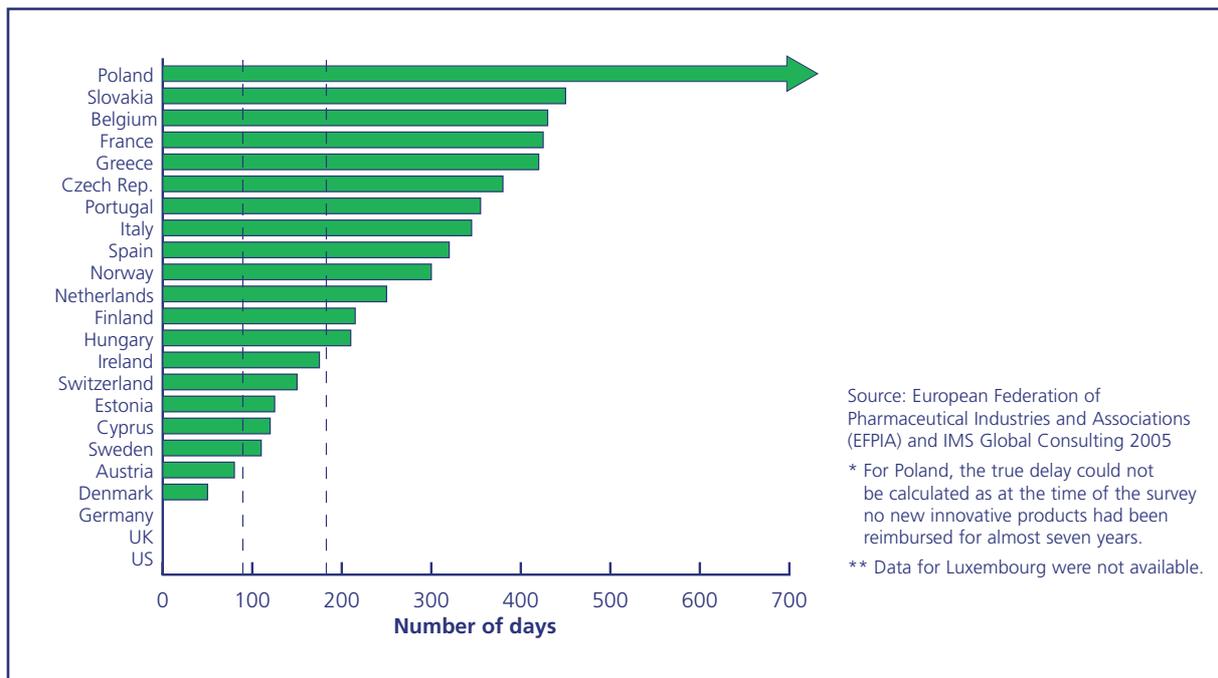
In a study of patients with schizophrenia in Stockholm county, one year following hospital admission, standardised mortality ratios for all causes of death were found to have increased 1.7-fold in men and 1.3-fold in women; deaths from cardiovascular disease increased 4.7-fold in men and 2.7-fold in women; and suicide rates increased 1.6-fold in men and 3.4-fold in women between 1976-1995 (Osby et al. 2000). The authors attribute these results to the move away from long-term inpatient care, where specialised psychiatrists treated both the somatic and psychiatric symptoms of their patients. During the study period, the number of hospital bed days associated with schizophrenia fell by 64%. Similar findings emerged from a Danish study. These findings suggest that **better training of community-based physicians on the physical health risks of persons with severe mental illness is urgently needed** (Mortensen et al. 1993).

## 4.5 Barriers in access to treatment

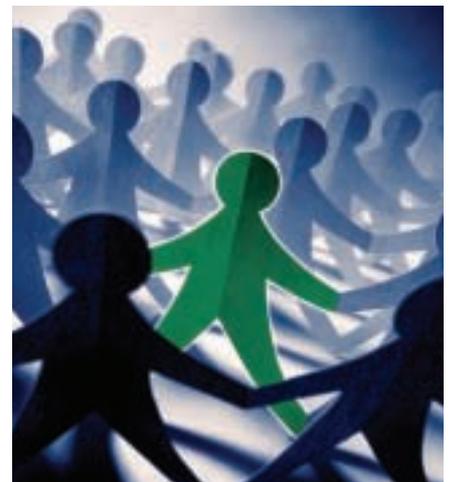
Barriers and inequities in access to medicines and psychological interventions are a critical issue across many countries.

Access to new medicinal treatments varies across Europe and reflects the significant differences in market access processes for medicines across the EU. The European Commission, through its G-10 High level Group on innovation and access to medicines, has recognised that harmonising access to innovative treatments across Europe is a key priority for the EU.

### Average time delay between marketing authorisation and effective market access across Europe\* – all products (marketing authorisation 30 June 2000 to 30 June 2004)



Inequities in access to medicines are also prevalent within countries. For example in Poland, insufficient amounts of antipsychotic medications are provided to hospitals, so that only some patients will access these drugs for free. Others have to buy them at their own expense in community pharmacies.



## 4.6 Links with other policies

### Integration at work

Rehabilitation centres and specialised work settings provide an important first step towards the integration of persons with severe mental illness into working life. But true integration would suggest that room for persons with severe mental illness is made, when possible, within the 'mainstream' workforce. **Such integration, however, is still a very distant goal for most countries in Europe.**

### Financial disincentives to integration

**Persons with severe mental illness tend to have low educational and skill levels thus their chances of sustainable employment are precarious at best.** Fear of stigma, discrimination and poorly adapted working environments may add to individuals' difficulties and reluctance to seek work.

Individuals with severe mental illness may sometimes have to forfeit some of their benefits if they seek integration into the workplace. In Switzerland for example, disability pensions, coupled with some other social financial support, may amount to nearly 3000 CHF (approximately €2000) per month. Persons with severe mental illness may need this pension to pay for sheltered housing. But if they seek employment, they must forfeit these benefits. This may represent a considerable financial risk for individuals (*P. Bovet*).

## 4.7 An imperfect legal framework

### The human rights context

Human rights discussions on severe mental illness tend to focus on the issue of enforced hospitalisation or institutionalisation. **Despite a common European legal framework, different countries have very different attitudes and legal boundaries determining enforced hospitalisation. Some countries require police and court injunctions to secure hospitalisation.** Higher rates of compulsory admissions for patients with severe mental illness may be seen in countries with a very paternalistic culture to health care. Patients and their carers may also be 'forced' into treatment options without being offered the chance to share decision-making.

### Arbitrary laws and policies

In many instances, the legal context governing entitlement to benefits is arbitrary. For example, according to Greek law, individuals with schizophrenia may only claim entitlement to their parents' pension (upon their death) if they were diagnosed with schizophrenia in a public hospital before the age of 18. For students engaged in higher education, this limit is set at age 24. This law goes against current clinical knowledge of the disease, in that diagnosis is usually made between the ages of 20 and 30. Moreover, **this arbitrary setting of an age limit is discriminatory, as similar age limits do not exist as a precondition to benefits entitlement for persons with other conditions.** (*R. Elgie, GAMIAN*)

# The way forward:

To move from policy formulation to local implementation, a series of lessons learned, precautions and recommendations may be drawn from experience so far across Europe. What follows is a proposed initial list of avenues for action. These actions are complementary: one should not be seen as more important than the other. Together, they may form the starting point for translating policies into local actions.

## 5.1 Framing policies

### Partnership for progress

All stakeholders – health professionals, social services, persons and their families, NGOs and policymakers need to work together to improve the care and facilitate social integration of persons with severe mental illness. Bridging across public, private and voluntary sectors is also critical.

### Innovative partnerships

Innovative partnerships may make significant strides in reaching target audiences. For example, in Poland priests are working with carers to help reduce the incidence of suicide. In France, the Mayors Association partnered with an advocacy group to think jointly about needed actions and reform.

### Bridging policy and practice

**A continuous dialogue is needed between those engaged in shaping policy and developing reforms and those involved in providing services on the ground.** To ensure their policies are grounded in reality, policy-makers need input from people in the field. Equally, the latter need policy-makers to orchestrate change.

### Speaking the same language

Much of stigma stems from ignorance, and much of non-compliance with treatment is due to mistrust or poor communication between the patient, carers and professionals. **All stakeholders need to speak the same language – and genuinely place the individual's needs at the core of all decisions and actions.**

### The power of shared values

Every aspect of care and services should be governed by a core set of values. These include:

- Tolerance and understanding
- Responsibility and accountability with regards to persons and their families
- Self-empowerment of persons with severe mental illness
- Respect and self-respect
- Professionalism and competence across all services
- Confidentiality
- Equal opportunities
- Team working and multidisciplinary.

(adapted from Estuar and selected interviews)

**In fact, these values not only need to infiltrate care settings, they should govern how all social institutions and public services deal with persons with severe mental illness. Several countries, for example, have invested in training programmes for the police force and judicial system.**

# avenues for action

## 5.2 Self-empowerment of persons and their families

### Joint training programmes for different stakeholder groups

As part of the LEONARDO Programme, sponsored by the European Commission, a number of training programmes have been set up targeting patients and family members together. The COPE programme, for example, involves 12 sessions of 2-3 hours for patients and family members on alternate weeks. The last week brings patients with their carers together in a joint session. Similar programmes include **Prospect**, a 12-country initiative developed by EUFAMI members which trains professionals, users and carers together and **Profamille**, run in Switzerland, which involves a set 10-week training programme for carers.

### Greater involvement of relatives in care decisions

Too often, carers are sidelined from treatment decisions and are left to deal with the consequences of treatment without any preparation. **Professionals need to engage and involve relatives as early as possible in consultations and in treatment decisions.**

### The power of advocacy: the United Kingdom

Re-think and SANE, two advocacy groups in the UK, have contributed significantly to improving the overall situation for persons with severe mental illness and their families. They have adopted a very proactive approach to advocacy, with measurable success, to improve availability of atypicals in schizophrenia and better access to treatment in general. **The psychiatric community is very much engaged with these organisations.**

### Better information about treatment possibilities

Misconceptions about the incurability of severe mental illness are still rife amongst policymakers, professionals, the general public and the media. Better information and communication about the possibilities of effective treatment is needed. This will significantly contribute to reducing stigma.

### Accompanying persons with severe mental illness

In Sweden, patient ombudsmen or 'companion' services termed 'Personliga Ombud' have been established within communities to help orient persons through the system and facilitate social integration on their own terms. (I. Nilsson, EUFAMI)

In Poland, there is a patient rights advocate within each individual hospital. Their role is to ensure that patients are aware of their rights and that these rights are respected throughout treatment.

### More accessible patient information materials

Good information is a critical facet of self-empowerment for patients and their families. Yet many people with severe mental illness are socio-economically disadvantaged. They may lack the literacy and skills to access and understand many of the information materials available. For example, in Poland it was found that only 50% of persons with mental health problems had a telephone (*R. Elgie*). Involving persons with severe mental illness and their families in the development of information materials may help produce more usable and accessible outputs.

## 5.3 Improvements in care

### Better training of psychiatrists and primary care physicians

**All professionals treating patients with severe mental illness require dedicated training to best address the needs of their patients.** Topics of particular relevance are communication with patients and their carers and recognition and treatment of the physical consequences of mental ill-health.

### Empowering new professional roles in the community

**In addition to physicians, we need well-trained mental health nurses, psychologists, and social workers in the community to ensure high-quality and coordinated care and support for persons with severe mental illness.** Governments need to invest in training, retention and recruitment of these professionals across all European countries.

### ‘Beating the symptoms of the illness is only half the victory’

Building self-esteem and developing a ‘dare to care’ attitude amongst patients and their families are as important as combating the symptoms or manifestations of disease. Professionals need to acknowledge and address these needs to optimise treatment effectiveness, increase probability of compliance and prevent relapse in patients with severe mental illness.

### Improve coordination between hospital and community care

**Upon discharge from hospital, patients are rarely guided to appropriate services in the community.** There is a need for more psychologists and mental health nurses within hospitals to support relatives and users, encourage compliance with medication and guide families to community services.

### Better provision of medicines within the community

More priority needs to be given to ensuring equal access to effective medicines in settings. These drugs constitute the core of treatment for persons with severe mental illness. Evidence of their clinical and cost-effectiveness must guide funding decisions. **Better planning of need within local drugs budgets is also needed.**

### Better provision of psychological therapies within the community

More priority also needs to be given to improving access to psychological therapies. Coverage of these therapies in primary care budgets must be ensured.

### Integrate psychiatric care within regular health care settings

Integrating mental health services within general hospital facilities may help remove some of the stigma associated with severe mental illness. It would also improve geographic access to facilities. However, **this integration is only possible if better training and availability of psychiatrists is ensured beyond the confines of specialist centres.**

*As was advocated in the European Commission Green Paper: ‘Mental and physical health are closely inter-related. One implication: Integrating mental health into the provision of general hospital care can significantly shorten hospitalisation periods, thereby releasing economic resources.’*

## 5.4 Funding and investment in community resources

### Engagement of public authorities to secure sustainability of NGO sector initiatives

One of the biggest challenges facing all NGO and voluntary sector organisations is the sustainability of funding. **Governments should recognise that the work carried out by such organisations fills a gap unmet by the public sector and contribute to their financial sustainability.**

#### Social integration in Romania

The Estuar Foundation is a Romanian Foundation set up in 1993 by the Romanian League for Mental Health and the Scottish Association Penumbra. Its mission is to 'provide social options and alternatives for adults with mental health problems for their reintegration within the Romanian community'. What is remarkable is that the organisation was set up at a time when social services were non-existent and recognition of mental ill-health was almost nil in Romania.

Amongst other things, Estuar provides working spaces and training in specific skills (carpentry, tailoring, traditional crafts) for persons with mental ill-health. It also provides supported living through four flats in Bucharest – **these flats are part of normal accommodation** and offer services for 12 people. Services include social and leisure activities, moral support, and expenditure administration.

The flats help Estuar accomplish one of its central goals: **'to encourage people with mental illness to take the risks of an ordinary life'**. (<http://www.ong.ro/long/estuar/>).

### Invest in community centres

Community centres are focal points for social integration. There, people with severe mental illness may develop skills, undergo training, and gain knowledge to seek work. **Policymakers need to invest in such community centres and services if they are committed to the social integration of people with severe mental illness.**

#### Service delivery by people with severe mental illness in Poland



The city of Krakow has encouraged entrepreneurship amongst people with schizophrenia. A hotel is run entirely by people with schizophrenia (*U Pana Cogito*) and a local theatre "Psyhe" group is composed solely of people with schizophrenia. (Association for the Development of Community Psychiatry and Care)

Hotel U Pana Cogito, Krakow, Poland  
Family Association of Mental Health

### Provide more sheltered accommodation

Sheltered accommodation is in short supply across Europe. Private sector and NGO initiatives, often run at the local level, have made the biggest inroads into improving availability of facilities. However numbers remain too low and financial sustainability remains a constant threat. **Public sector investment is needed to allow social integration through accommodation in a more systematic way across societies.**

## 5.5 Networks for exchange

### Create opportunities for patient exchange

One of the most important tools against isolation is exchange and dialogue. Persons living with severe mental illness benefit greatly from engaging with others in the same situation. **Patient exchanges around medication, for example, seem to encourage greater compliance.**

### Sharing and exchanging best practice across Europe

Running an NGO can be isolating, with too much attention focused on securing funds and little time for strategic thinking. **Forums facilitating networking and exchange between NGOs can be tremendously helpful to advocacy groups.**

The EU may play a pivotal role in facilitating exchange across countries – this is, in fact, one of the expressed proposals set forth in the Green Paper.

#### Learning from the success of depression

Much can be learnt from the success stories in combating depression. The European Alliance against Depression (EAAD) has sponsored the creation of regional networks of information between the health sector, patients and their relatives, community facilitators and the general public. The aim of these networks is to reduce depression and suicidal behaviour in the community. In pilot projects, decreases of 25% in suicides and suicide attempts have already been observed.

#### Sharing best practice across NGOs

The European Patient Forum initiated a training programme to provide the necessary skills to help local groups interested in creating a patient organisation. These training courses teach participants how to establish an organisation; what the legal requirements are; how to put together a business plan; how to develop lobbying skills, and so forth.



## 5.6 Research

### More longitudinal studies and comparative research

Several initiatives have been launched to collect systematic information across countries on risk factors, care patterns and outcomes of persons with severe mental illness. National registries which allow for cohort studies over time may prove invaluable for longitudinal research. Further insights are needed to understand long-term trends and determine the impact of system reforms, changes in the delivery of care and other policies on the quality and outcomes of care.

In addition, we need a better understanding of the cost-effectiveness of different treatment and care options to help guide efficient allocation of resources. Such data may also help overcome cost-containment barriers in funding.

*Existing EU-led networks of information and surveillance present excellent opportunities for ensuring high-quality information collection that may guide local policies and enable cross-country comparisons using common sets of indicators.*

#### Strong data driving policy – the case of Finland

STAKES, the Finnish National Research and Development Centre for Welfare and health, has ensured excellent links between government and the research community. Its project MindFull involves the systematic collection of information on mental ill-health across several European countries. The goal is to build strong evidence to guide practice and policies. **The project demonstrates the power of good information in raising awareness and understanding of severe mental illness and its treatment.**

## 5.7 The role of the EU

### European influences

The European Union, through its various bodies, may apply pressure to national health and social affairs ministers to meet standards set at a European level. Through exchange and networks, it gives a stimulus for national-EU partnerships. Finally, the EU has a role to play in setting and raising treatment standards, issuing guidelines and recommendations and providing training for professionals across Europe.

# In conclusion...

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At the heart of all initiatives to improve care for persons with severe mental illness, whether it is through community-orientated treatment, initiatives to reduce stigma, better funding for mental ill-health or improved training for professionals and carers, lies the issue of their **empowerment and social integration**.

Most European countries are still affected by the closures of large mental institutions over previous decades. Although a shift to community care is to be welcomed, the considerable gaps in treatment created by this often ill-managed switch still persist today. The greatest shortage in most countries appears to be in services that bridge across social care and healthcare.

Much can be done at a national or devolved regional level. As a priority, we urge governments to:

- **Make mental health a priority in European, regional and national level policies**
- **Lead in challenging discrimination and stigma** of severe mental illness in laws, practice, societal values and access to care.
- **Raise awareness and understanding of severe mental illness** across society, with targeted initiatives for different groups.
- **Invest in mental health** services and professional training
- **Improve access to mental health treatments to the highest possible level across Europe**
- **Invest in social reintegration programmes** for people with severe mental illness who are re-entering the community
- **Ensure good coverage of sheltered housing and community schemes** for the entire population corresponding to local need
- **Provide training** for all specialist and non-specialist health and social care staff working with people with severe mental illness, as well as for families and carers
- **Engage persons with severe mental illness and their families** in the development of policies, information materials and service provision.
- **Facilitate the exchange of ideas** and sharing of best practice through networks and consortia.
- **Help NGOs with funding** at an EU, national, regional and local level, and recognise the important resource they represent.

Local solutions to the challenges of severe mental illness have made an enormous difference within local communities. These local partnerships will, to some extent, need to evolve organically if they are to be effective.

National and regional policy makers can make the difference by ensuring those local actors who **dare to care** are resourced, connected to others, listened to, and above all, respected.



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# Interviewees

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