



Background document for the thematic conference :

“Promoting Social Inclusion and Combating Stigma for better Mental Health and Well-being”

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**“Promoting Social Inclusion and
Combating Stigma for better
Mental Health and Well-being”**

PROMOTING SOCIAL INCLUSION AND COMBATING STIGMA FOR BETTER HEALTH AND WELL-BEING

BACKGROUND DOCUMENT TO THE EUROPEAN COMMISSION THEMATIC CONFERENCE

The Thematic Conference “Promoting Social Inclusion and Combating Stigma for Better Health and Well-Being” will, firstly, consider the social determinants of mental health and well-being and of inequalities in mental health in the EU. Secondly, it will consider measures to provide the necessary social support to people with mental health problems and to prevent their stigmatisation and social exclusion.

The conference background document is divided into two parts:

Document 1 – Key Messages and Actions, provides an overview of the priority area, suggests essential actions for Member States and gives key messages and actions in the 5 sub-themes of the conference.

Document 2 – Supporting Background Papers, complements the key messages and actions by providing more detailed and referenced information. This document is organised in two sections:

- Two chapters exploring cross cutting themes that are relevant to all of the sub themes.
- Five chapters, covering each of the conference sub-themes, developed by an expert in that area.

Both documents were developed through several rounds of consultations with key stakeholders.

PROMOTING SOCIAL INCLUSION AND COMBATING STIGMA FOR BETTER HEALTH AND WELL-BEING

BACKGROUND DOCUMENT TO THE EUROPEAN COMMISSION THEMATIC CONFERENCE

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http://ec.europa.eu/health/mental_health/policy/index_en.htm

A great deal of additional information on the European Union is available on the Internet. It can be accessed through the Europa server (<http://europa.eu.int>).

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PROMOTING SOCIAL INCLUSION AND COMBATING STIGMA FOR BETTER HEALTH AND WELL-BEING

DOCUMENT 1 – KEY MESSAGES AND ACTIONS

Introduction

In recent years, mental health and well-being have become valued assets at the individual, community and societal level. Mental health and emotional well-being form a significant and indivisible part of people's health and quality of life. Likewise, stigma and discrimination relating to the experience of mental distress represents a potential harm on those same levels.

As Europe strives to regain economic growth, there are opportunities to promote well-being in the systems created, and to ensure that austerity measures do not compromise the rights, care or treatment of people with mental health problems.

Complex mixes of environmental, biological, and social determinants affect individual well-being. A number of risk and protective factors have been identified. Some groups in society are more exposed to risk factors than others. These groups are often the same groups towards whom wider health inequalities strategies are addressed.

Poverty and structural inequalities are particularly associated with poor well-being, and there is good evidence that multiple discrimination (e.g. on grounds of race, age or sexual orientation) and other factors such as poor housing or unemployment increase the level of risk for mental health problems. In recognising that social determinants affect mental health, it is critical that the lived experience of social risk factors is not pathologised.

Medically-diagnosed mental disorders constitute a significant proportion of the illness and disability burden in the EU, both in terms of the cost of treating mental illness and in the cost of managing co-morbid health conditions, which are more prevalent in this population. Mental disorders impose high human costs on people in terms of suffering, and economic and non-financial burdens on both health and social systems. It is important to recognise that many people who experience mental distress are never diagnosed with a mental illness, and may not agree with the medicalisation of distress.

In addressing mental health, and supporting people who experience mental distress, it is important to consider that the language used to talk about mental health is not universal. Actions to reduce stigma and reduce inequalities have to be mindful that there are diverse viewpoints amongst stakeholders whose voices need to be heard, most importantly those people with direct personal experience of mental distress.

It is important to realise that health actors cannot be solely responsible for the integration of well-being into other policy areas, but that intersectoral collaboration is vital. Mental health policy makers should be mindful of, and advise where necessary on wider strategies, like poverty reduction initiatives, that will have an effect on mental health. Where the delivery of non-health initiatives involves people experiencing mental illness, for example in disability discrimination, or labour market inclusion, mental health stakeholders should work as partners with other areas to achieve outcomes. Likewise, actors in other non-health policy areas should be mindful of, and advise where appropriate, on the development of mental health activities.

Essential Actions

As a basic set of principles to start action in the area of promoting social inclusion and combating stigma, moving forward from the statements on this priority area outlined in the European Pact for Mental Health and Well-being (see annex 1) and the 2009 European Parliament Resolution on Mental Health (see annex 2), Member States, in cooperation with the relevant stakeholders, should aim to:

- **Consider the promotion of people's emotional well-being a central objective of policy making and an indicator of its success:** Design social policies and interventions both within and outside the health sector which strengthen social inclusion, recognising it as a protective factor of mental health and well-being which prevents the stigmatisation and discrimination of people or population groups. Action should be informed by evidence, and mindful of the need to balance the role of the state and the role of individuals and communities.
- **Assign responsibility for mental health and well-being actions and coordinate policies and services provided through different sectors:** Define a person or structure with the overall responsibility for state/governmental activities in mental health and well-being, and create mechanisms which ensure the co-ordination of policies and services defined and delivered through the different sectors involved, such as health, education, social protection and social inclusion.
- **In parallel, address the challenge of co-morbidities, including the compounded stigma and social exclusion resulting from combined mental and physical health problems, or from multiple sources of discrimination.** Implement specialised education programmes targeted at key state agencies under their authority to improve attitudes and practice of staff delivering health and social protection services to those with mental health problems.
- **Move towards comprehensive community-based services for people experiencing mental health problems, away from large mental health institutions:** Develop and promote universally accessible, transparent mental health services of high quality that are focused on recovery. These will usually be community based, minimally restrictive/coercive and delivered alongside other healthcare in partnership with a range of health, educational and social stakeholders.
- Ensure, through legislative measures, that people with mental health problems have equal access to basic human rights and the benefits of citizenship by **adopting and implementing the UN Convention on the Rights of Disabled People**. This ensures human rights in relation to care and treatment as well as ensuring equal access to employment, education and other activities. When implementing legislation and policy, care should be taken to identify indirect discrimination against people with mental health problems which may be occurring as a consequence, and to monitor the impact of these measures.
- **Include people with direct experience of mental illness (including carers)** in designing, implementing and evaluating services, interventions, anti-discrimination activities and stigma reduction campaigns: Enable people affected by mental health problems (both individuals and their families) to be empowered to act as partners in care, treatment and recovery, and as advocates in anti-discrimination work.

- **Run sustained, flexible, evidence-informed public anti-stigma programmes** that are linked to and supported by meaningful anti-discrimination measures with regards to mental health issues. These campaigns should be targeted at groups of people who evidence shows are particularly operative in reducing discrimination, such as healthcare staff, children, and employers.
- **Monitor mental health, public attitudes and experiences of discrimination at the local, national and international levels:** Monitor population mental health using validated instruments via large-scale population surveys and measure, public attitudes towards mental illness and the experience of stigma and discrimination and disseminate information on the prevalence and nature of prejudice and discrimination against people with mental health problems.

1. Social Protection, Social Inclusion and Mental Health –

Successful nations are built on the foundation of strong communities. Good mental health is critical to the success of communities, and therefore to the success of nations.

Promoting social inclusion and social protection, promotes the subjective mental health and well-being of people, builds the capacity of communities to manage adversity, and reduces the burden and consequences of mental health problems. Widespread disadvantage damages the social cohesion of communities and societies by decreasing interpersonal trust, social participation and civic engagement.

Country institutions matter. Social protection systems with a reasonable minimum wage and a well-regulated financial system guarantee a socially acceptable minimum income and avoid financial exclusion. Well-designed, active, labour market policies protect the mental well-being of those unemployed, whilst also improving the efficiency of the labour market.

Actions:

- *Include mental health outcomes as well and indicators in the collection of national, regional and local strategic policy outcomes. Where possible and relevant these should include indicators of well-being identified at community level, and indicators of recovery developed with people with lived experience of mental illness.*
- *Assess social and economic policy also in terms of its future impact on mental well-being, by bringing immediate economic savings at the cost of future health and economic productivity.*
- *Invest in social protection systems as a means of increasing population mental well-being, particularly in times of recession when higher levels of unemployment are unavoidable. Provide social transfers alongside active labour market policy and activation measures.*
- *Enforce cooperation and transfer of knowledge across Member States using existing methods such as a strengthened open method of coordination with a focus on the influence of social institutions on mental well-being and dissemination and sharing of information across institutions.*

2. Breaking the Cycle of Discrimination due to Mental Health Problems –

People with mental health problems are stigmatised, socially and structurally excluded, and thus hindered from realising their abilities.

People with mental illnesses are also at greater risk of experiencing physical health problems such as obesity, which is in itself stigmatising. The additional stigma amplifies the burden for individuals and their surroundings and tends to isolate them further.

Countering stigmatisation needs to be a cross-sectoral political task.

Any stigma reduction activities should include a) people with mental health problems in its conception, delivery and evaluation and b) contact with people with mental health problems (utilising social contact theory) in its realisation.

Actions:

- *Facilitate and promote direct contact and interaction with people who have lived experience of mental health problems (utilising social contact theory). Combine it with education addressing existing misconceptions about mental illness e.g., about causes of mental illness, to maximise effect.*
- *Consider a combination of different (educational) methods and media, and address different levels, individuals, groups and society, with the aim of sustaining the effect and bringing about structural changes.*
- *Involve people with mental health problems in the conception and implementation of any campaign and intervention, in order to raise self-esteem and empowerment and to challenge entrenched social attitudes.*
- *Develop concrete actions for students which can overcome prejudice and stigmatising attitudes more easily and are an important target group for long-term change in social attitudes and behaviours.*

3. Routes to Recovery: Employment and Meaningful Activities –

Work is a key element in the recovery process for the majority of people with mental health problems.

Mental health problems are the first or second most common reason for long term disability benefits in European countries.

Social welfare benefit systems in Europe can act as major impediments to participation in work. They need to be flexible so as to provide incentives for individuals to seek work.

Supported employment schemes can be effective in helping people return to work, if well implemented. Integration with mental health services and secure funding are important facilitators.

Employment is not an immediate option for all people with mental health needs. Support and opportunities to engage in meaningful activities also have an important role to play; this can strengthen skills and confidence that may be part of their journey of recovery.

Actions:

- *Provide supported employment initiatives, such as the Individual Placement and Support (IPS) interventions, which seem to be both more effective and more cost-effective than traditional vocational rehabilitation schemes.*
- *Support social firms which are organised by people with lived experience of mental illness, and can benefit from public sector advice and seed funding to help kick-start their activities.*
- *Promote awareness of disability and anti-discrimination legislation among employers, especially small organisations, those without a human resources department and trade unions.*
- *Tailor social protection system rules to the needs of people with mental health problems, e.g. making social protection systems more flexible to help encourage individuals to seek work if they so wish, whilst ensuring that they can reclaim benefits quickly if required.*
- *Train employment service staff to better understand the needs of jobseekers with mental health needs, and to support employers in recruiting these people.*
- *Promote activation mechanisms in the labour market policies, which combine a range of regulatory measures and economic incentives for individuals and employers*
- *Strengthen action to tackle discrimination in the workplace, through concrete actions such as monitoring of the extent to which people with mental health needs are being recruited, promoting legal proceedings in situations where discrimination can be identified or giving publicity to legal cases of discrimination.*

4. Rights, Responsibility and Citizenship –

People with mental health problems and their relatives should be empowered and enabled to execute their fundamental rights as citizens, as well their human rights in relation to care and treatment.

People with mental illnesses are at greater risk than the general population of certain physical illnesses, such as obesity, diabetes and cardiovascular disease, and yet they are less likely to be diagnosed or treated for these diseases.

Societies must strengthen their efforts to overcome legal, administrative, societal, economic or other barriers that prevent people with mental health problems from enjoying full and equal participation.

Restriction of the rights, liberties and choices of people with mental health problems, in relation to care and treatment or legal capacity, because of their need for treatment or public safety concerns, should be undertaken with extreme caution and following the principle of least restrictive option. Compulsory treatment should be subject to rigorous legal scrutiny regarding its medical appropriateness and adherence to national and international law.

Actions:

- *Promote the concept of citizenship through the action of adequate agencies and the provision of funding. Ensure advocacy services for people with mental health problems are in place.*
- *Promote and facilitate the action of membership organizations with democratic norms and strongly tied to local communities, such as consumer-operated service organisations or self-help agencies, which can act as a locus of empowerment and citizenship.*
- *Intensify the implementation of legislative provisions which promote and safeguard the rights of persons with mental problems and advocate for their international recognition and adoption.*
- *Assure regular evaluation of national legal frameworks and mental health legislation. A close collaboration of the Legal or Criminal Justice System and Mental Health System is beneficial when shaping new laws or adapting legal frameworks.*
- *Promote the inclusion of lived experience of and narrative research by people with mental health problems into mental health policy processes and decision making, as well as the access of those with mental health problems to information on their rights and support.*
- *Promote the extension and standardisation of National and European data reporting and information systems to reflect the rights and their violation of persons with mental health problems.*

5. Comprehensive Health and Social Support for People with Mental Health Problems –

The availability of accessible primary care mental health services is a precondition to the social inclusion of people with mental health problems. Holistic community-based health services should be age and gender appropriate and delivered as part of a community partnership which includes government, civil society and social protection services.

People with mental health problems and their relatives/carers have to be involved as equal partners in all service delivery aspects including, inter alia, service design, implementation, management and evaluation.

Because experience of mental illness is itself a risk factor for certain physical illnesses and for inequalities, a Public Mental Health Plan with a whole system approach for recovery and empowerment should be developed and delivered.

The provision of safe, evidence-based care, delivered in partnership with patients, must be maintained even throughout cuts in public spending. Addressing mental health problems and their knock-on effects delivers substantial savings across a range of policy areas.

Actions:

- *Improve access to adequate care by financial and geographical solutions, including for instance the foundation of community care on local structures and systems that integrate health services across specialties and with social systems and community organisations.*
- *Plan, conceive and develop community based mental health care as a complete system of care, using a community development approach which builds sustainable partnerships with local communities.*
- *Develop comprehensive intersectoral policy and support practices which require intersectoral partnerships involving various local authorities (municipalities, locally elected mayors), community organisations, users, family members and business leaders, with primary and secondary health care services.*
- *Provide and promote good access to information, advocacy and human rights defence, as a key to users' empowerment.*
- *Recognise that not everyone who experiences mental distress wishes to subscribe to the medical model of care and treatment. Recovery can come from a range of activities including participation in the arts, advocacy, self-management, and collective action. Authorities should give financial and capacity building support to user-led and non-medical interventions. This should include support to develop and disseminate evidence of effectiveness.*

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DOCUMENT 2 – SUPPORTING BACKGROUND DOCUMENT

CROSS CUTTING THEME: SOCIAL INCLUSION AND MENTAL HEALTH

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Social Determinants of Mental Health

Mental well-being is an asset of individuals, communities and populations. It is an asset whose value is subject to change throughout the life course. The concept of ‘mental capital’ has been developed as a means of describing the ‘net worth’ of an individual in terms of their mental health over the life course¹. Just as economic capital is affected by a range of determinants throughout life, so mental capital is a function of our genetic endowment, our experiences, and the environment in which we live. Over recent years it has become increasingly clear that high levels of mental well-being in the population in general are associated with greater productivity, better relationships, and consequentially a greater contribution to economic growth, and reduced call on services such as criminal justice and health.

Mental health is subject to a range of socially determined risk and protective factors, some of which can be modified:

RISK FACTORS	Unemployment, poverty, inequality, discrimination, poor housing, poor early years experience, violence, abuse, drug and alcohol abuse, poor general health, caring responsibilities (which are all higher among socially excluded populations and contribute to social exclusion)
PROTECTIVE FACTORS	Employment, social protection, resilience, social capital from social networks, engagement in community, positive community engagement with mental health issues, hope, optimism, goals, good general health, good quality parenting, positive relationships in childhood and protection from childhood neglect and abuse (which are all lower among socially excluded populations and further eroded by social exclusion)

In general, poor living conditions such as poverty, debt, deprivation or unemployment, as well as other conditions linked to social exclusion, are corrosive of individual mental well-being². Moreover, people with mental health problems are more likely to experience physical health problems, which can further compromise the efforts of the individual in an already disadvantaged situation. When the experience of mental illness is the cause or a factor in the experience of exclusion, the effects can be still more damaging.

An emerging body of literature is exploring the links between different forms of inequalities, deprivation and of social exclusion, with poor mental well-being and the distribution of mental illness^{3,4}.

Associations between social position and prevalence of common mental disorders have been described in a number of studies, with clear but modest (around 1.5 and 2 times) increases of risk in those from less privileged groups, including those with poor education, unemployment or material deprivation⁵.

Although mental health problems have been generally found to be associated with lower material standards of living, a more direct effect of income related inequalities on mental health has not been conclusively established. Some studies and preliminary data reveal higher prevalence of common mental disorders in regions or nations with greater income inequalities⁶ (e.g., as expressed by Gini coefficient), which persist even among those groups with highest incomes⁷. This research also suggests that the extent of the impact of income-related inequality for mental health problems could be higher than that reported for general health⁸.

Social isolation is also seen to be an important factor in mental ill-health⁹ and there is evidence on the links of social support and the risk of mortality, with results from meta analytic studies showing a 50% increase in the likelihood of survival in people with stronger social relationships (which exceeds many well-known risk factors for mortality, such as obesity or physical inactivity)¹⁰.

In her paper 'Mental Health, Resilience and Inequalities'³, Lynne Friedli explores in detail the interactions between individual and social factors influencing resilience to mental distress. Interestingly, the author points to several studies^{11,12} which indicate that social support and participation do not mediate the effects of material deprivation. Rather she draws on an ecological study of 23 countries which showed that absolute and relative income was of greater importance to mortality, infant mortality and life expectancy¹³. Friedli draws on further evidence to show that the effects of community circumstances on mental health are not insignificant, and that indicators of community conflict and fragmentation as well as neighbourhood problems influence health outcomes independently of Socioeconomic status^{14,15}. Powerlessness, mistrust, and the risk of violence also contribute to the levels are key, showing that the context of the community in which people live can be as important as individual circumstances.^{16,17}

While the direct correlation between income inequalities and the prevalence of mental health problems still remains a matter of debate, requiring further research¹⁸, it is indisputable that mental ill-health and social exclusion are closely linked, and that measures to improve mental health and resilience may promote social inclusion, and vice versa.

There is evidence indicating that risk factors for mental health problems and disorders will increase in European populations due to the current financial crisis.¹⁹ Times of economic instability cause psychological stress, which is linked to both the onset and course of mental illnesses.²⁰ Unwelcome changes in life circumstances, such as threat of redundancy, unemployment, and unmanageable debt are strongly linked to depression, anxiety disorders, and suicide.^{21,22} The effects are modified by experiences like shame at losing one's job and financial hardship^{23,24}.

The European Commission conducted a special Eurobarometer survey on mental health and well-being²⁵ to support the implementation of the Pact. A representative sample of 26,000 EU citizens in 27 EU member states was consulted during February and March of 2010. The results showed a pattern that was observed throughout the sample, where people in self reported lower

socioeconomic groups as well as those with less years of education or facing financial hardship experienced more disruption in daily activities from mental health problems (fig 1).

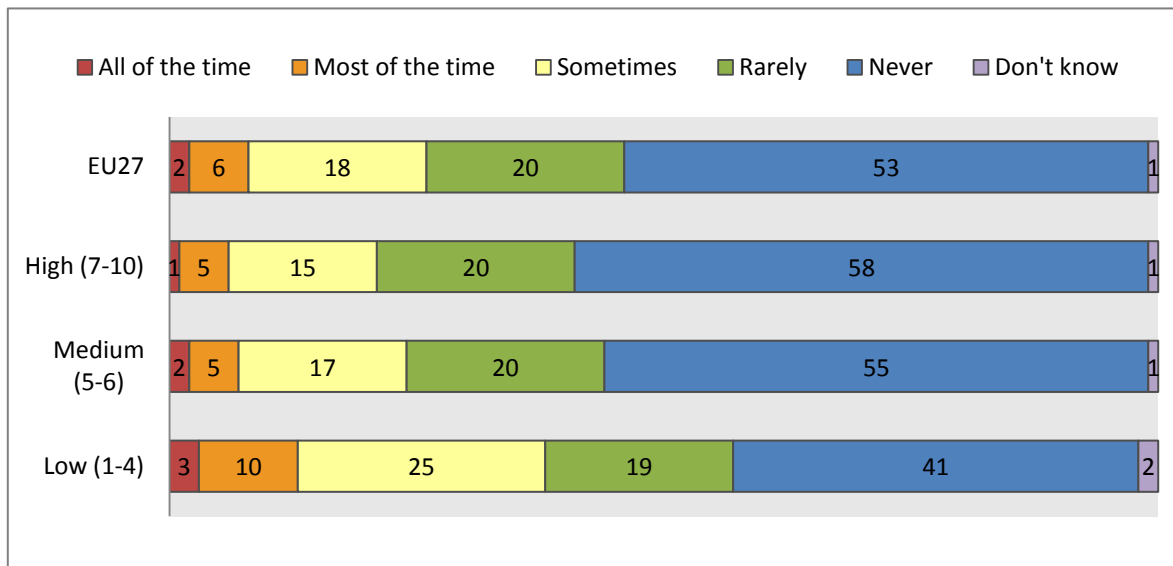


Figure 1, showing responses to the question “During the past two weeks how often have you had any of the following problems in your day to day life: You have accomplished less than you would like as a result of an emotional problem (such as feeling depressed or being anxious)”, broken down by self-reported social group Special Eurobarometer 345²⁵

Additional findings from this survey reveal that:

- There had been a downturn since December/January 2005/6. Those with the most negative experience are those for whom life is more socio-economically difficult (low (1-4) social groups and those who have difficulties paying their bills ‘most of the time’). Those with a more positive experience of life are at the higher end of the social scale (high (7-10), in social groups who ‘almost never’ have difficulties paying their bills, are in any employment or are younger (15-24 year olds, students).
- Those affected by physical or emotional problems tend to be those under social and financial stress; that is, those from low (1-4) social groups and those who have difficulties paying their bills ‘most of the time’.
- The profile of those seeking help reflects the profile of those who tend to experience emotional problems: those who live alone, who have difficulties paying their bills ‘most of the time’ and come from lower (1-4) social groups.
- At a socio-demographic level, those feeling most at risk in their jobs, that their job role does not match their skills and that they are not recognised for what they do, tend to be those who are most financially stretched; those who have difficulties paying their bills ‘most of the time’ and lower (1-4) social groups. They also more strongly represented among those who have sought help for an emotional problem and those who have taken antidepressants in the last year.

Well-being as an outcome measure for policy and society

Since the Lisbon Treaty, 'promoting the well-being of its peoples' is included as a primary objective of the European Union.²⁶ Initiatives to look into measuring well-being as an indicator of social success, alongside economic indicators have been conducted at a range of levels^{27,28,29,30}. Interest in mental health is growing and several Member States have commissioned major research work to consider the role of mental well-being in the formulation and delivery of national objectives, such as the UK (Foresight³¹).

Social exclusion, health inequalities and poverty, particularly relating to inequity are key issues at the European and Member State levels. Well-being and mental health are important mediators in all of these issues, and should be integrated into systematic efforts to address these issues in the population, and in specific groups within the population as part of the EU2020 Strategy.

Mental Illness in Europe

Poor mental health and the burden of mental illness are major factors undermining the ability of society to maximise its potential. Mental illness affects around 27% of Europeans in any given year, an estimate of some 83 million Europeans affected annually³². In addition to a wide prevalence, mental disorders have a large footprint in terms of disease burden and cause of disability. The direct and indirect economic costs of poor mental health are significant, with 2005 estimates of around €386billion for the EU25 plus Norway, Sweden and Iceland³³.

Neuropsychiatric disorders are the second cause of disability-adjusted life years³⁴ (DALYs) in Europe and account for 19%. Unipolar depression accounts for 5.6% of all DALYs, and self inflicted injuries account for 2% of all DALYs. Mental disorders are by far the largest contributor to chronic conditions afflicting the population of Europe. According to the most recent available WHO data (2004), neuropsychiatric disorders rank as the first cause of years lived with disability (YLD) in Europe, accounting for 39.7% of those attributable to all causes. Unipolar depressive disorder alone led to 12.4% of all YLD, making it the leading chronic condition in Europe. Alzheimer's and other dementias are in fifth place, accounting for 3.9% of the total. Schizophrenia and bipolar disorders rank 12, and are each responsible for 2.3% of all YLD.

Whilst the absolute numbers of people affected by more severe mental disorders may be small, the effect in terms of DALYs and YLD are severe, and it is the people whose mental illness is most disabling and most extended who are at greatest risk of exclusion as a result.

Most people can and do recover from mental illness, when given hope, and the appropriate support. Care and treatment should reduce the level of symptoms of mental disorder. Holistic care and treatment also improves the mental well-being of people with mental illness and enables individuals to continue to flourish as active citizens and contribute to the society in which they live.

Stigma and Discrimination in Europe

The experience of developing a mental illness at any age can undermine the potential of a person to function in society as an active citizen. The symptoms of mental disorders often lead to disability, damage to social networks, and the erosion or failure to acquire vocational or interpersonal skills so necessary for life in the European society of today and envisaged by the Europe 2020 strategy. Occasionally, the diagnosis and treatment for mental disorders can also have unwanted effects on the individual's social and functional capacity through stigma.

The social stigma and the linked social exclusion of people affected by mental illness are far reaching:

- Stigma and social exclusion discourage people from accessing support services to enable them to recover and move on in life.
- Stigma and discrimination contribute to a cycle of self-stigma and withdrawal which erodes mental well-being further and exacerbates social exclusion.
- Children and young people who experience mental illness may be separated from peers in special schools or facilities. They frequently find it hard to acquire transferable skills and qualifications that enable them to become active and productive citizens as adults.
- Public attitudes to mental illness are still poor in many countries. Misconceptions about dangerousness, competence, and recovery prospects can lead to low public sympathy for spending on mental health services, poor tolerance of people with mental illness in the community, and increased isolation and discrimination.
- Negative attitudes and discrimination are not limited to the public. There is evidence that stigma and discrimination are present individually and structurally in health services, social protection systems, and public policy.
- Stigma and social exclusion limits the extent to which people affected by mental illness are able to contribute to the economy through employment, or other gainful activities such as caring for children or engaging in lifelong learning.

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Background

Stigma and discrimination faced by people with a mental illness is widespread¹ and offers a key public health challenge. Stigma (plural stigmata) was originally used to refer to an indelible dot left on the skin after stinging with a sharp instrument, sometimes used to identify vagabonds or slaves²³⁴. More recently, stigma has come to mean 'any attribute, trait or disorder that marks an individual as being unacceptably different from 'normal' people with whom he or she routinely interacts, and that elicits some form of community sanction'^{5,6,7}.

In terms of the stigma of mental illness, this is usually considered to be an undesirable attribute in terms of social normality⁵. This has been an area of research for many decades and has been reported since Ancient Greece⁷.

Understanding stigma and discrimination

There is now a voluminous literature on stigma^{8,9}. The most complete model of the component processes of stigmatisation has four key elements⁹: (i) Labelling, in which personal characteristics are signalled or noticed as conveying an important difference; (ii) Stereotyping: the linkage of these differences to undesirable characteristics; (iii) Separating, the categorical distinction between the mainstream or normal group and the labelled group as in some respects fundamentally different and (iv) Status loss and discrimination: devaluing, rejecting and excluding the labelled group. Interestingly, more recently, the authors of this model, Link and Phelan, have added a revision to include the emotional reactions which may accompany each of these stages¹⁰.

Research has established that mental illness is more stigmatising than physical illnesses^{11,7} and that more stigmatising attitudes are directed towards people diagnosed with schizophrenia compared with depression¹² and eating disorders¹¹, demonstrating not only that mental illness is more stigmatising than physical illness, but also the existence of a hierarchy of stigma within psychiatric diagnoses. Moreover, it is important to recall that people with a mental illness tend to live with other illnesses as well – for example, obesity – which are in themselves stigmatising.

Stigma can be seen as an overarching term that contains three important elements:

- problems of knowledge → ignorance
- problems of attitudes → prejudice
- problems of behaviour → discrimination

Ignorance: the problem of knowledge

At a time when there is an unprecedented volume of information in the public domain, the level of accurate knowledge about mental illnesses (sometime called 'mental health literacy') is meagre¹³. In a population survey in England, for example, over half of the people (57%) believe that the statement 'someone who has a split personality' describes a person who is mentally ill¹⁴. A majority (64%) thought that 10% of the population or fewer would experience a mental illness at some time in their lives.

There is evidence that deliberate interventions to improve public knowledge about depression can be successful, and can reduce the effects of stigmatisation. In a campaign in Australia to increase knowledge about depression and its treatment, some states and territories received an intensive, co-ordinated programme, while others did not. In the former, people more often recognised the features of depression, were more likely to support help-seeking for depression, or to accept treatment with counselling and medication¹⁵.

A series of government surveys in England has been carried out from 1993 to 2009 and gives a mixed picture. On the one hand, there are some clear improvements over time, for example, the proportion thinking that people with mental illness can be easily distinguished from 'normal people' fell from 29% to 19%¹⁴. On the other hand, views became significantly *less* favourable over this time for several items, e.g. "we need to adopt a more tolerant attitude to people with mental illness" decreased from 92% to 87%. An increase in knowledge about mental illness thus does not necessarily improve either attitudes or behaviour towards people with mental illness.

Prejudice: the problem of negative attitudes

Although the term prejudice is used to refer to many social groups which experience disadvantage, for example minority ethnic groups, it is employed rarely in relation to people with mental illness. The reactions of a host majority to act with prejudice in rejecting a minority group usually involve not just negative thoughts but also emotion such as anxiety, anger, resentment, hostility, distaste, or disgust. In fact prejudice may more strongly predict discrimination than do stereotypes.

Interestingly, there is almost nothing published about emotional reactions to people with mental illness apart from that which describes a fear of violence. A fascinating exception to this is work carried out in the South Eastern region of the USA, in which students were asked to imagine meeting people who either did or did not have a diagnosis of schizophrenia. All three physiological measures of stress (brow muscle tension, palm skin conductance, and heart rate) were raised during imaginary meetings with 'labelled' compared with 'non-labelled' individuals. Such tension was also associated with self-reported negative attitudes of stigma towards people with schizophrenia. The authors concluded that one reason why individuals avoid those with mental illness is physiological arousal, which is experienced as unpleasant feelings¹⁶. Additionally, a recent paper has compared the emotional reactions towards people with mental illness in Germany between 1990 and 2001. It was found that in regards to schizophrenia, there was more anger and fear in 2001 than in 1990 and in regards to depression there was also an increase in these negative feelings, as well as more positive emotions such as compassion and friendliness¹⁷. More research is clearly needed in the area of emotional responses to mental illness as this could be a definitive factor in the social distancing that people with mental illnesses often feel.

Discrimination: the problem of rejecting and avoidant behaviour

Attitude and social distance surveys usually ask either students or members of the general public what they would do in imaginary situations or what they think 'most people' do, for example, when faced with a neighbour or work colleague with mental illness. Although important lessons have flowed from these findings, this work has emphasised what 'normal' people say without exploring the actual experiences of people with mental illness themselves about the behaviour of 'normal' people toward them. Further it has been assumed that such statements (usually on knowledge, attitudes or behavioural intentions) are congruent with actual behaviour, without assessing such behaviour directly. Such research has usually focussed on hypothetical rather than real situations, neglecting emotions and the social context, thus producing very little guidance about interventions that could reduce social rejection.

Stigma as a barrier to help seeking

Despite the high numbers of the general population who could be diagnosed with a mental illness, only a proportion of these actually seek professional help for these problems¹⁸. According to health behaviour theory, a person will seek help for a problem if they believe that the problem is severe enough to interfere with their daily lives; that treatment will reduce symptoms and that there are no major barriers to help seeking¹⁹. A major barrier for not seeking help is seen to be the stigma associated with being diagnosed with a mental illness^{20,21,22} along with the associated embarrassment of consulting relevant professionals²³ and the consequences individuals envisage regarding, for example employment and relationships. Individuals believe that seeking help is akin

to admitting that they can not cope; the likelihood of seeking help for a physical problem is higher than for a mental health problem, suggesting that seeking help for mental health problems is seen as particularly stigmatising. The consequences of failure to seek help include a continuation and perhaps worsening of symptoms and the continuation of stigma²⁴, as well as the degradation of general health, for example with the onset of obesity, diabetes and cardiovascular diseases which go undiagnosed and untreated. (See sub-section 4)

Diagnostic overshadowing

Research has shown that those with mental illness have high rates of co-morbid medical diseases and that these diseases often go untreated or even undiagnosed²⁵. Ultimately, risk of premature death both from natural and unnatural causes has been found to be higher in people with mental illness²⁶. The term 'diagnostic overshadowing' refers to when a clinician attributes physical symptoms to a patient's mental illness²⁷. Research commissioned by the Disability Rights Commission found that in England and Wales, people with mental illness were more likely than other people to have heart disease, high blood pressure and diabetes. Additionally, it was found that people with serious mental illness were more likely to have coronary heart disease or stroke by age 55 and those diagnosed with schizophrenia were almost twice as likely to have bowel cancer²⁸. Although more research is needed to ascertain exactly why diagnostic overshadowing occurs, it is clear that that patients with mental illness are at a higher risk of developing serious medical illnesses and that these illnesses will not be treated.

Global patterns of stigma and discrimination

Do we know if discrimination varies between countries and cultures? The evidence here is stronger, but still frustratingly patchy²⁹. Although studies on stigma and mental illness have been carried out in many countries, few have compared two or more places, and few have included non-Western nations³⁰.

Most of the published work on stigma is by authors in the USA and Canada^{8, 9, 11, 31}, but there are also a few reports from elsewhere in the Americas and in the Caribbean³². In a review of studies from Argentina, Brazil, Dominica, Mexico, and Nicaragua, mainly from urban sites, a number of common themes emerged. The conditions most often rated as 'mental illnesses' were the psychotic disorders, especially schizophrenia. People with higher levels of education tended to have more favourable attitudes to people with mental illness. Alcoholism was considered to be the most common type of mental disorder. Most people thought that a health professional needs to be consulted by people with mental illnesses³³.

What different countries do often share is a high level of ignorance and misinformation about mental illnesses. A survey of teachers' opinions in Japan and Taiwan showed that relatively few could describe the main features of schizophrenia with any accuracy. The general profile of knowledge, beliefs and attitudes was similar to that found in most Western countries, although the degree of social rejection was somewhat greater in Japan³⁴.

A recent study used the Discrimination and Stigma Scale (DISC) in a cross-sectional survey in 27 countries using language-equivalent versions of the instrument in face to face interviews between research staff and 732 participants with a clinical diagnosis of schizophrenia³⁵. The most frequently occurring areas of negative experienced discrimination were: making or keeping friends (47%), discrimination by family members (43%), keeping a job (29%); finding a job (29%), and intimate or sexual relationships (29%). Positive experienced discrimination was rare. Anticipated discrimination was common for: applying for work or training or education (64%); looking for a close relationship (55%), and 72% felt the need to conceal the diagnosis. Anticipated discrimination occurred more often than experienced discrimination. This study suggests that rates of experienced discrimination are relatively high and consistent across countries. For two of the most important domains (work and personal relationships) anticipated discrimination occurs in the absence of experienced discrimination in over a third of participants. This has important implications: disability discrimination

laws may not be effective without also developing interventions to reduce anticipated discrimination, for example by enhancing the self-esteem of people with mental illness, so that they will be more likely to apply for jobs.

Conclusions

If we move our point of reference from stigma to discrimination, there are a number of distinct advantages. First attention moves from attitudes to actual behaviour, not if an employer *would* hire a person with mental illness, but if he or she *does*. Second, interventions can be tried and tested to see if they change behaviour towards people with mental illness, without *necessarily* changing knowledge or feelings. The key candidates for active ingredients to reduce stigma are: (i) at the local level, direct social contact with people with mental illness^{36, 37, 38}; and (ii) social marketing techniques at the national level. Third, people who have a diagnosis of mental illness can expect to benefit from all the relevant anti-discrimination policies and laws in their country or jurisdiction, on a basis of parity with people with physical disabilities. Fourth, a discrimination perspective requires us to focus not upon the 'stigmatised' but upon the 'stigmatiser'. In sum, this means sharpening our sights upon human rights, upon injustice and upon discrimination as actually experienced by people with mental illness^{39, 40, 41, 42}.

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Key messages

- Successful nations are built on the foundation of strong communities. Good mental health is critical to the success of communities, and therefore to the success of nations.
- Promoting social inclusion and social protection, promotes the subjective mental health and well-being of people, builds the capacity of communities to manage adversity, and reduces the burden and consequences of mental health problems. Widespread disadvantage damages the social cohesion of communities and societies by decreasing interpersonal trust, social participation and civic engagement.
- Country institutions matter. Social protection systems with a reasonable minimum wage and a well-regulated financial system guarantee a socially acceptable minimum income and avoid financial exclusion. Well-designed, active, labour market policies protect the mental well-being of those unemployed, whilst also improving the efficiency of the labour market.

The Problem

- The Policy Context

It is increasingly realised that high levels of mental health not only contribute to individual well-being but also contribute to economic growth. Social exclusion, health inequalities and poverty are key issues within the European Union and, since the Lisbon Summit 'promoting the well-being of its peoples', has been included as one of the primary objectives of the European Union.

- Mental well-being is more than the absence of mental illness

Positive mental health and well-being is more than the absence of mental illness. Positive feelings about oneself and others, a sense of meaning and purpose in life and good relationships with others all contribute to positive emotional and social well-being at the level of the individual. Positive mental health is an asset to individuals which contributes to physical health, less drug and alcohol use and increased employment and earnings^{1,2} but also contributes to communities and society at large through increased interpersonal trust, social participation, social support and civic engagement^{3, 4, 5}.

- Poor living conditions increase perceived social exclusion and damage mental well-being

Positive mental well-being increases individual and community resilience to adversity and disadvantage, but poor living conditions are corrosive of social inclusion and mental well-being⁶. Low income, poverty, debt and deprivation significantly increase individuals' sense of exclusion, increase psychological distress⁷ and the likelihood of experiencing common mental disorders⁸. Unemployment in particular has been shown to be extremely damaging to mental well-being, in part

through its impact on income and resources but also through its effects on social status and social roles.

- Poor living conditions damage social capital, whilst social support acts as a buffer

Social support moderates the relationship between poor living conditions, social exclusion and mental well-being. Social support both as moral support and financial assistance promotes a sense of inclusion and provides a 'buffer' against psychological distress which can lead to poor mental well-being⁷. However, over time, low income and detachment from the labour force can reduce social participation at the individual level and damage social capital in communities experiencing high levels of unemployment⁹.

- Social institutions matter

Although markers of social disadvantage such as low education, poor skills and lower income are associated with perceived social exclusion and worse mental well-being across countries, country institutions make a difference. For a given level of deprivation, the citizens of Scandinavian states such as Sweden and Denmark have lower levels of perceived exclusion and better mental well-being than countries of roughly equal national income⁶.

- Social protection and labour market policy can help

Better outcomes in some countries are not an accident. Where eligibility for welfare payments is wider and replacement rates relative to previous income are higher, mental well-being among the unemployed is improved. Low-level, means-tested benefits increase levels of distress and hinder the job-search process¹⁰. Active labour market policies such as skills training and employment subsidies not only improve the likelihood of moving back into employment, but also improve mental well-being compared to passive welfare assistance¹¹.

- Country wealth helps but the distribution of income may also be important

Country wealth contributes to better mental well-being by reducing the citizens' experience of deprivation and also by funding the development of better healthcare, education and social protection systems that contribute to better mental well-being. However, there is an emerging research literature that suggests that in wealthier countries, greater equality of income distribution is associated with fewer social problems, higher levels of trust and an increased sense of social inclusion leading to better mental well-being¹².

What works:

- *Governments should assess social and economic policy in terms of its impact on current and future mental well-being. Immediate economic savings in cutting welfare benefits services and reducing financial deficits may be bought at the cost of future health and economic productivity.*
- *The influence of social institutions such as welfare agencies on mental well-being is complex and mediated through a country's culture and history, but a strengthened open method of coordination with a focus on this area could help Member States learn from what works in other jurisdictions and start to understand why.*

- *Investment in social protection systems is an investment in the asset of population mental well-being, particularly in times of recession and low aggregate demand when higher levels of unemployment are unavoidable. However, social transfers must be provided alongside activation measures (e.g., benefits reduce over time and are time limited, training) and active labour market policy.*
- *The higher levels of positive mental well-being enjoyed by the wealthier European nations can be shared with the new member and candidate countries through the European Social Fund. However, the model of economic and social development is important. Innovative and competitive private enterprise flourishes within a society where social problems are shared through inclusive policies and social responsibilities are recognised.*

Examples of Policy and stakeholder initiatives

- Bring together actors in health and social care to mainstream mental health and well-being.

Box A. Activities of the European Social Network under the PROGRESS programme.

ESN is supported by the European Commission under the PROGRESS programme for the period 2008-10 and its present activities include:

- *Long-term care:* a working group in 2008 and a series of e-newsletter articles on key issues for the elderly.
- *Active inclusion:* a working group in 2008 leading to a brochure on implementing active inclusion, a case-study report and a strong contribution to the Commission's active inclusion recommendation.
- *Children & families:* a working group in 2008-09 leading to brochure on key aspects of policies to support vulnerable children and families.
- *Contracting for quality:* a policy and practice research leading to a report on the dynamic funding relationships between financier, provider and user of elderly care services – this was an issue which emerged from the long-term care working group.
- *Developing community care:* this strand consisted of a working group and a high-level advisory group and is leading to a campaign to promote the deinstitutionalisation of care services.
- *Mental health:* mental health has been a cross cutting issue in the policy work carried out by ESN which in 2009 organized the seminar "Building partnerships in mental health for economic and social integration". In 2010, ESN launched a new working group on mental health, which is currently analysing how local health and social services have a wider impact on people's well-being and may improve life quality of people with mental health problems.

Why this matters: *ESN is a European organisation drawing together managers in health and social care, a key group for ensuring that mental health and well-being are mainstreamed. The organisation provides a route both for the sharing of good practice between members, and for reaching those members with new ideas.*

- Indicators for well-being allow the connection of mental health to national priorities

Box B. National indicators for mental health (Scotland)

Scotland has developed a set of national indicators for adult mental health following an evidence-led consultation process. A data set has been identified from national population

surveys for 12 of fourteen indicators (Reliable data for Emotional Intelligence and Spirituality were not available). The indicators have been operationalised, with data now available for the first time.

Mental well-being is assessed at a population level using the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) to assess mental well-being.

A national outcomes framework for mental health and well-being has been developed using a logic model approach. This associates the short, medium and long term outcomes of public mental health activities in a range of policy areas to the core national outcomes as set by the Scottish Government.

Local Government in Scotland has responsibility for a range of community, health and social functions. Local authorities are required by the Scottish Government to provide 'Single Outcome Agreements' which demonstrate the way that they will meet outcomes specified by the Government. These outcomes include public mental health measures.

Why this matters: *The Scottish Government has allied mental health outcomes to national priorities, and has developed and implemented an indicators framework for demonstrating these outcomes. Connecting mental well-being to national and local outcomes is crucial for mainstream adoption of the concepts.*

- Target approaches at minority groups at risk of discrimination and social exclusion

Box C. Minority programme, Ireland

In Ireland, the national suicide prevention strategy, *Reach Out*, recognises the importance of tackling minority stress among marginalised groups and names lesbian, gay bisexual and transgender (LGBT) people, asylum seekers, refugees, homeless people and members of the traveller community as being 'at risk' of suicide. The Irish mental health policy, *A Vision for Change*, also recognises minority stress and identifies the need to respond to the mental health needs of minority groups. The National Office for Suicide Prevention in Ireland funds a number of mental health promotion and suicide prevention initiatives targeting minority groups such as LGBT people and members of the traveller community. Other EU Member States such as the United Kingdom have highlighted minority groups as being in need of specific attention in both mental health and suicide prevention policy.

Why this matters: *Minority groups are subject to discrimination of different types. There is good evidence for the negative effect discrimination on any grounds has on mental health. For some groups, multiple discrimination, or discrimination on grounds of mental illness combined with racism, homophobia or other action have a compound effect. Targeted approaches for specific population groups can be effective and are necessary in order to meet the mental health needs of minority groups..*

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2. Breaking the Cycle of Discrimination due to Mental Health Problems

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Key message

- People with mental health problems are stigmatised, socially and structurally excluded, and thus hindered from realising their abilities.
- People with mental illnesses are also at greater risk of experiencing physical health problems such as obesity, which is in itself stigmatising. The additional stigma amplifies the burden for individuals and their surroundings and tends to isolate them further.
- Countering stigmatisation needs to be a cross-sectional political task.
- Any stigma reduction activities should include a) people with mental health problems in its conception, delivery and evaluation and b) contact with people with mental health problems (utilising social contact theory) in its realisation.

The problem

Although stigmatisation is a potential issue for any one living in the EU, and one in four can expect to experience a mental health problem during his or her lifetime, people affected by mental health problems are being stigmatised in almost all areas of their daily life. They are socially and structurally excluded and hindered from realising their abilities, coping with the normal stresses of life, working productively and fruitfully, and being able to make a contribution to their community.¹

- *People with mental health problems are being stigmatised in all areas of their life*

Though mentally ill people report being supported by partners, friends, and the family, stigmatisation affects almost all areas of their lives, including social networks like neighbourhoods, acquaintances, friends, partners and family members, in education, the media², economic relations with employers, and co-workers, professionals in the social system (health insurance, social welfare office and federal employment, media², police³, and judiciary (e.g., family court)⁴. Especially notable is the reported stigmatisation in the psychiatric and general medical care system and by professionals.⁵

- *People with mental health problems are confronted with prejudice*

People with mental health problems are confronted with the prejudice, including belief that they are dangerous, likely to be involved in criminal violence, act unpredictably⁶, are expected to not be able to achieve much⁷, and that the experience of mental illness is somehow their fault or due to weakness, the latter also leading to self-stigmatisation on the side of the affected people.

- *Frequent stigmatisation leads to anticipated stigmatisation*

The frequent experience of stigmatisation leads to the fact that people with mental health problems very often anticipate stigmatisation, and thus act in a way as to avoid stigmatisation and discrimination, by not seeking help or support⁸, or by not applying for a job.

- People with mental health problems also stigmatise themselves (self-stigmatisation)

Additionally, being themselves part of society at large, and thus to an extent sharing society's convictions, people with mental health problems tend to stigmatise themselves. This might be seen in the fact that, for example, people are more willing to accept a diagnosis of burnout than depression, feel shame at having a diagnosis, and have low self-esteem.

- Stigmatisation leads to exclusion with even more negative consequences

Stigma, prejudice, anticipated stigmatisation, and self-stigmatisation open up a vicious circle of social and economic exclusion and discrimination with a higher than normal risk of late treatment (e.g., because people seek help too late⁹), under-treatment (e.g., because doctors tend not to recognise mental health problems¹⁰), and co-morbidity, unemployment¹¹, poverty¹², homelessness, and loss of self-esteem. In addition, since discrimination and exclusion of any sort increases the risk of mental illness, people with mental health problems are at higher of experiencing a situation that fosters a mental disorder.

- Lack of treatment in primary and psychiatric care

Especially notable is the problem of under-treatment, that the majority of people with a mental disorder do not even come into contact with mental health services.^{13,14,15} This is due to the fact that in primary care, mental disorders are often not recognised, and that there is a misconception of the low possibility of a cure, or that affected people are reluctant to come into contact with health care because of anticipated stigmatisation.

- Social inclusion still needs to be promoted

Although the de-institutionalisation and the integration of psychiatric wards into hospitals is advancing throughout Europe, people with mental disorder are neglected in most national action plans on social inclusion, the reason being, among others, that the main focus regarding mental illness still is its cure, neglecting the need for social inclusion of the people concerned, with its positive side effects.¹⁶

- The individual's and the economic costs of stigmatisation are high

Due to stigmatisation and social and economic exclusion the individual's costs in terms of disability adjusted life year (DALY), and also costs for the society, the welfare system and the economy are high. The latter is due mainly to the loss of productivity, but also due to costs for, for example, treatment and cure, education, higher-than-average-rate of homelessness.¹⁷

- People in contact with mentally ill people also experience stigmatisation

Stigmatisation is so strong, that not only mentally ill people, but also family members, partners, and personnel working in psychiatric settings experience stigmatisation¹⁸ (sometimes called secondary stigmatisation).

- Due to stigmatisation mental health issues have low priority in policies

Due to primary and secondary stigmatisation finally policies in the field of mental health issues have low priority.¹⁹ However, since stigmatisation is a factor in almost every area of the lives of the affected, countering stigmatisation needs to be a cross-sectional political task.

What works

There are many efforts to counter stigmatisation and social exclusion, but there is lack of evaluated interventions²⁰. A study in Germany, for example, showed that only 30% of the few evaluated interventions used a control group and only very few included a follow up study.²¹

- Social distance as indicator for stigmatising attitude and behaviour

The main indicator for the reduction of stigmatisation is the reduction of the wish of social distance to mentally ill people,²² since it directly relates to actual behaviour.

- Pupils, students and health professionals seem to be a good target

Students and pupils seem to be able to overcome prejudice and stigmatising attitude more easily than other groups,²³ and are an important target group to change attitudes and behaviour, because changes in attitude and behaviour will take place already at an early age. Also health professionals seem to be a group that is easy to de-stigmatise.

- Public protest campaigns risk an attitude rebound

There is little validated data about the effects of open protest against stigmatising and discriminating depictions of mentally ill people. However, protest campaigns run the risk of an attitude rebound, and thus may increase discrimination in some part.²⁴

- Contact to people with mental disorder is the most effective way to overcome social distance

Studies show that the most effective way to reduce stigma and social distance is direct contact and interaction with affected people. People are more accepting, and regard people with mental illness as less dangerous, if they have had personal contact or acquaintance with affected people. Additionally, the effect in such cases is sustained, and more likely to lead to a change of attitude and behaviour.²⁵

- Including mentally ill people in the conception and realisation of action fosters empowerment

People with mental illness should also be involved in the conception and implementation of any campaign and intervention, in order to raise self-esteem and empowerment.²⁶

- Education and information – combined with contact – is most effective

The most effective intervention on the individual level is education addressing existing misconceptions about mental illness and improving knowledge, e.g., about causes of mental illness, combined with personal contact. However, referring only to biogenetical explanation models can also increase fear and the desire of social distance.²⁷

- A combination of methods is effective

A combination of different (educational) methods and media should be included in the intervention.²⁸

- Addressing different levels, individuals, groups and society, helps sustain the effect

Interventions to de-stigmatise mental illness should work on different levels at the same time in order to achieve sustained societal and structural changes, and to reach the society and specific

groups of persons.²⁹ Different levels are the societal level (deeply rooted stereotypes), the interpersonal level (wish to strengthening group identity; perception of unjustified privilege for some stigmatized groups) and the individual level (lack of knowledge or fear of the stigmatised person).³⁰

- *All in all the most successful interventions include:*

The provision of information about the stigmatised group, the opportunity for personal contact or other elements that facilitate perspective-taking, the change of methods and media, and the promotion of new social norms (e.g., through a role-model, legislative changes or non-stigmatizing depiction in the media).³¹

Examples of Policy and stakeholder initiatives

- School-based anti stigma campaigns – target young people for sustained and greater effects.

Box A. School – based anti-stigma programmes, Germany, Slovakia and Czech Republic

BASTA³²

The German learning package "The Mentally Ill" for pupils between 13 and 17 years includes contact not only to a person with mental illness, but also with their relatives, and professionals.

Irrsinnig Menschlich (Insanely Human) e.V.³³

The project "Crazy? So what!": Mental Health – Health Promotion, Prevention and Anti-Stigma Work in Schools" has been developed in Germany and is now also being executed in Slovakia and the Czech Republic.

Why this matters: *Evidence shows that addressing stigma early has a positive effect on young people as they grow. There is also anecdotal evidence to suggest that reaching young people has an effect on the attitudes of others in the household.*

- Break the cycle of discrimination at work – target managers.

Box B. Bundesverband der Angehörigen psychisch Kranker e.V. (family self-help)³⁴

The project "Psychisch krank im Job. Was tun?" is a training programme for managers to learn how to deal with people with mental health problems at the workplace setting. It includes as an integral part contact with affected people.

Why this matters: *As theme 3 below shows, fear of disclosure is a major factor inhibiting people with mental health problems from seeking support at work. Accessing managers in a business focused manner helps to create mental health promoting workplaces.*

- Attract media attention with universal public campaigns, community events and festivals.

Box C. Public events and festivals on mental health themes

Mental Health Weeks, Austria³⁵, **Germany**³⁶, **Italy and others**

Mental Health Weeks play a significant role in community education about mental health and illness, and bring people with mental disorder, relatives and family members, as well as professionals together and in contact with the wider public. During the "Woche der Seelischen Gesundheit" in Berlin, Germany, for example, hospitals and other institutions open their doors,

and thus interact with the general public and society, and people from the general public can get first-hand information about the psychiatric system.

Mental health Arts and Film Festival, Scotland

The festival, with more than 200 events up and down the country, from music and dance to film, comedy and theatre, aims not only to challenge perceptions of mental health, but to stimulate debate and collaboration between the arts and mental health professionals. The goal is not one of protest but of trying to increase awareness of the positive contributions people with mental health issues can and have made.

The starting point, three years ago, was to look at addressing stigma towards mental health problems with the public as a whole. The festival's reach now also extends beyond its three-week programme, with a series of year-round projects inspired by work and collaborations started during its run.

Why this matters: *Campaign weeks and days and events can draw media attention to activities and issues. Public-focused events can increase the contact people have with mental health as a concept, decreasing social distance and demystifying mental illness and services.*

- Encourage user-led and grass-roots initiatives.

Box D. Mad pride, Ireland³⁷

Organising “Mad Pride Ireland Family Fun Days” brings people with and without mental disorder together in a welcoming setting, and is also attractive for the media to report about in a positive, non-discriminatory fashion. The model is now being expanded to other European countries.

<http://www.madprideireland.ie/>

Why this matters: *Mad Pride Ireland is a concept which originated with one individual and built into a movement for social change. It shows that anti-stigma actions can be based around simple concepts, be public focused, and can originate from and grow amongst people with lived experience of mental ill health.*

- Combine multiple approaches and sustained strategies.

Box E. “1 in 4”, Andalusia, Spain

“1 in 4” is a strategy against the stigma of mental illness started in 2006 in Andalusia (Spain). It is composed of a set of long term awareness actions, designed to modify the stigmatising perceptions and attitudes from general public as well as from segmented target audiences. These specific audiences, selected after reviewing scientific literature and the internal debate, have a fundamental role to reverse the discrimination and social isolation processes in favour of social inclusion towards one of the most unprotected collectives in society. These specific audiences are

- Media professionals: It is estimated that general population receives 90% of their mental health information through the media. Their reflection of the reality of mental illness, free of prejudices and stereotypes, contributes to normalize it and place it

properly in society.

- Health professionals: Work is currently done with mental health professionals, as they play an important role in tackling stigma through their relationship with people with mental illness. These professionals are crucial to identify self-stigma process and reduce it with their support and encouraging recovery. Next steps will focus on working with the primary care and emergency staff and the non-clinical staff in the services.
- Adolescents: Achieving positive perceptions during these years may mean changing the perceptions of future society. In this age, the change of attitudes or prejudices is more effective and it's also a chance to develop positive attitude skills which might turn negative if they're not worked on.
- People with mental illness. Actions over this group are related with reducing self-stigma and to favour the social recovery process and to give them empowerment and participation tools. Helping to strengthen the users' association movement is also a priority goal.

Together with these actions for specific audiences, '1 in 4' also develops actions addressed to general population.

Why this matters: *Sustainable, flexible anti-stigma campaigns should engage different audiences, and uses a variety of methods.*

- Evaluate attitude changes and effects over time.

Box F. See me, Scotland

The Scottish "See me" Campaign against stigma and discrimination associated with mental health was launched in October 2002 as a part of the Scottish Executive National Programme for Improving Mental Health and Well-being. The core objective of the campaign is to raise public awareness how stigma and discrimination affect people with mental health problems by challenging individual incidents of discrimination, involving people in anti-stigma activities at both national and local levels and ensuring that the voices and experiences of persons concerned are heard. The campaign has a highly sophisticated internet presence³⁸.

While being effective in promoting an overall culture of learning and evaluation, the campaign sees a major future challenge in addressing discrimination embedded in processes and practices of organisations and agencies. An external evaluation of the campaign was carried out in 2008³⁹

Why this matters: *'see me' is one of the most sustained anti-stigma campaigns in Europe. It has received government support through successive public mental health policy initiatives, and has used both external and internal evaluation to adapt to changes in social attitudes, methods of communication, and focus over time. In this way it has remained relevant, targeted and effective.*

- Strategies using multiple programmes and focusing on personal contact

Box G. "Time to change", UK^{40,41}

In January 2009, two mental health charities, MIND and Rethink, launched the largest ever programme in England to combat mental health stigma and discrimination, with the Institute of

Psychiatry as the evaluation partner. A key aim of the Time to Change programme is to reduce stigma by facilitating social contact between members of the general public and people with mental illness on a large scale. This is particularly significant as it addresses two limitations of previous social contact research: 1) The difficulty of reproducing social contact interventions on a large scale and 2) the difficulty of evaluating the results of social contact interventions in naturalistic rather than experimental settings. Although the Time to Change national programme aims to include principles of social contact across the board, three projects in particular demonstrate the potential for facilitating social contact on a large scale in a naturalistic setting:

- **Get Moving!** comprises a week of over 100 mass participation physical activity events which are advertised throughout the community as a call to action against mental health stigma. These bring together diverse members of the community both with and without experience of mental illness in an informal, real-world setting with optimal conditions for social contact to be effective in reducing stigma (equality common goals, mutual cooperation and institutional support)
- At the **Living Library**, individuals who have experience of mental illness volunteer to wear T-shirts with their diagnosis written on the back, illustrating how the general public often use diagnoses as a label and do not see the individual behind it. Members of the public can then 'check out' a volunteer to have a half an hour conversation about that person's experiences.
- **Education Not Discrimination (END)** is a targeted anti-stigma training programme delivered to medical students, trainee teachers and educational professionals throughout England. In addition to a lecture on mental health stigma and various interactive activities, participants receive talk by one or more volunteers with experience of mental illness.

<http://www.time-to-change.org.uk/>

Why this matters: *Time to Change brings together best practices from Scotland, New Zealand and other established anti-stigma activities. The campaign is generously funded by mainstream charitable foundations, including 'Comic Relief', which is an annual public fundraising event in the UK. The NGO led campaign is being evaluated rigorously.*

Box H. See Change, Ireland

SEE CHANGE is Ireland's new national campaign and partnership to reduce stigma and challenge discrimination associated with mental health problems. Led by an NGO, it was launched in April 2010. See Change is an alliance of organisations working together through the National Stigma Reduction Partnership to bring about positive change in public attitudes and behaviour towards people with mental health problems.

At the national level, See Change will launch a media campaign, specifically pursuing a social marketing and online strategy. At the local level, See Change consists of a network of national and local organisations across the country carrying the key messages to communities through local events, broadcasts, local print media and a range of other activities.

Amnesty International (Irish Section), in partnership with See Change unveiled its brand new social marketing campaign to help challenge mental health prejudice and end discrimination, which will be seen on billboards, bus shelters and in newspapers across the country. The campaign is asking everyone to play a part in challenging mental health prejudice, by taking a

pledge, taking action or attending a community event.

<http://www.amnesty.ie/mentalhealthdiscrimination>

EU Projects

Anti-Stigma Programme: European Network (ASPEN)

ASPEN is a three year project co-funded by the Public Health Programme, with five lead sites working with twenty test sites across Europe. In the third year of three the project objective is to assist in reducing the stigma of depression across the 27 EU Member States.

The outcomes of the project will be available from autumn 2010 until the project conclusion, and will add considerable value to EU level activities on stigma and discrimination.

- The project has further developed and refined a validated tool for measuring stigma, the Discrimination and Stigma Scale (DISC), used to assess individual's experience of stigma. This was validated in a previous pan-European large scale survey (INDIGO <http://www.forschungsportal.ch/unizh/p5857.htm>).
- The project is finalising a profile of stigma in Europe, having used a range of tools including DISC and measures of well-being and function to interview service users in twenty field sites across Europe.
- The project will shortly publish a good practice guide based on extensive surveys of literature and practice in the test sites.
- The project will produce comprehensive resources on the barriers to employment for people with mental health problems, and on involving civil society in mental health policy. These will be available early in 2011.

Deliverables from the ASPEN project will be made available online from

<http://www.mdac.info/aspenttp://www.mdac.info/aspent>

Best Practice In Promoting Mental Health In Socially Marginalized People In Europe (PROMO)

Promoting mental health and preventing mental-ill health among the increasing groups of socially marginalized people is a major challenge to European societies. There are various policies and services to achieve this in member states, but information on what constitutes best practice is fragmented and consistent guidelines do not exist. PROMO brings together a multidisciplinary consortium of experts from 14 diverse member states (covering more than 85% of the total EU population) to consolidate the knowledge in the field and identify best practice.

It will consider six different factors of social marginalization, review legislation and policies, and – focusing on major cities – assess systems of health and social services for the people concerned. PROMO will define guidelines for best practice and disseminate the findings widely among the relevant stakeholder groups in Europe. Finally, it will highlight barriers for the implementation of the guidelines and suggest solutions.

For further details of the PROMO Study visit: <http://www.promostudy.org/>

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3. ROUTES TO RECOVERY: EMPLOYMENT AND MEANINGFUL ACTIVITIES

Invited author: David McDaid (London School of Economics and Political Science, UK)

Key messages

- Work is a key element in the recovery process for the majority of people with mental health problems.
- Mental health problems are the first or second most common reason for long term disability benefits in Europe.
- Social welfare benefit systems in Europe can act as major impediments to participation in work. They need to be flexible so as to provide incentives for individuals to seek work.
- Supported employment schemes can be effective in helping people return to work, if well implemented. Integration with mental health services and secure funding are important facilitators.
- Employment is not an immediate option for all people with mental health needs. Support and opportunities to engage in meaningful activities also have an important role to play; this can strengthen skills and confidence that may be part of their journey of recovery.

The EU's Europe 2020 strategy puts an emphasis on the contribution that can be played by all of European citizens to economic growth. Actions that can help facilitate the greater participation of people with mental health needs in the workforce, not only can help contribute towards the 2020 goals, but can also help reduce the need for Member States to spend scarce resources on social protection measures. This goal cannot be achieved without comprehensive action to address discrimination in employment, with attitude change coupled to effective legislative protection under disability discrimination legislation.

The problem: a low rate of labour force participation

Work is one of the most important elements in the recovery process for the majority of people with mental health problems. It is associated with improved health outcomes, self-esteem and quality of life^{1,2,3}. In addition, it also promotes social inclusion and additional life opportunities for an individual as a result of having a higher disposable income. Conversely exclusion from work is likely to lead not only to poverty, but also a loss of confidence, an impoverished social network, and a sense of being without any social value.⁴

Research indicates that the majority of individuals with severe mental health problems want to work in regular employment settings, with up to 90% of users of psychiatric services wanting to enter or return to work.⁵ Despite this, individuals with mental health problems experience multiple barriers to both obtaining and maintaining employment. In the EU as a whole almost two thirds of the adult population are in employment⁶, ranging from 54% in Malta to 77% in the Netherlands. However rates of employment for people with all types of mental illness lie between 18% and 30%. Rates of employment are lowest for those with psychotic disorders such as schizophrenia (the majority of whom are capable of and wish to work). They are little more than 10% in countries including the UK, Germany, the Netherlands and Poland^{7,8}.

In England individuals with mental health problems historically have had a 40% lower chance of obtaining employment compared to those with physical disabilities⁹. It is however important to note that people with mental health problems make a major contribution to society, not only through paid

work, but also through voluntary activities. In England one in five may engage in voluntary work, and the groups who are least likely to be paid for their work (particularly people with bipolar disorder or schizophrenia) are those most likely to be working in a voluntary capacity¹⁰.

The costs of exclusion from the labour market are high, not only to people with mental health problems and their families, but also to governments who have to pay out long disability benefits to those with mental health problems. In many European countries poor mental health is now the first or second most common reason for disability benefits¹¹. In Great Britain alone, in 2007 40% of all claims for disability benefit were for mental health problems. This was greater than the entire number of unemployment claimants, at a total cost in excess of €1500 million¹².

Of course, for some people with mental health problems, return to the mainstream labour markets may not be the best solution in the short or medium term. For these people community activities, volunteering and lifelong learning can enable the development of transferable skills and confidence, from which capability and confidence for eventual employment may develop.

The problem: the barriers to employment?

Stigmatising attitudes in the workplace

There is strong evidence that stigmatising attitudes towards people with mental health problems, by both employers and employees, persist in the workplace. Employers may be reluctant to take on individuals with known mental health problems believing that they are likely to be less productive or more disruptive in the workplace^{13 14}. For instance, a survey of 100 small employers in Greece reported a common perception that it was easier for people with severe debilitating diabetes or severe kidney disorders to gain employment compared to people with schizophrenia or depression¹⁵. In Ireland, surveys have shown that more than a quarter of employers feel that employing people with mental illness may adversely impact on other employees. 54% of employers think that organisations take a significant risk when employing people with mental ill-health; 34% of employers thought that people with mental ill-health were less reliable, and 39% of employees agreed with this statement¹⁶.

Fear of consequences of disclosing mental health status

People with mental health problems may also be reluctant to enter employment for fear of having to disclose their condition. One survey in Scotland found that 57% of those who had experienced mental illness had concealed the fact when applying for a job. Some 43% had not gone ahead with a job application for fear of how their mental health history might be perceived¹⁷. Some employers discriminate against applicants who declare a history of psychiatric treatment. In a study of 200 Human Resource Officers in UK companies, vignettes of job applicants were submitted which were identical except for the presence or absence of a diagnosis of depression. The mention of a mental illness significantly reduced the chances of employment, compared with a history of diabetes. This differential treatment was made based upon perceptions of potential poor work performance, rather than expectations of future absenteeism¹⁸. While disclosure may reduce chances of employment, without disclosure an individual cannot request support and modifications to help them maintain employment. Even without direct disclosure, it may still be difficult to explain gaps in employment history to any prospective employer.

Employment and training organisations may lack the skills to help support people with mental health needs

In contrast with physical disabilities, firms may lack the technical knowledge and awareness of what is required to accommodate people with mental health problems in the workplace. For example, surveys in Ireland and Scotland respectively reported that 75% and 70% of employers respectively agreed that they did not know enough about the law regarding mental health in the workplace.^{19 20} They may also receive insufficient support and disability awareness information to help

accommodate people. This may also reflect a lack of capacity or understanding about the needs of people with mental health problems among public employment services.

Legislation to prevent discrimination in the workplace difficult to enforce

Although anti-discrimination legislation exists across the EU, it does not appear to be as effective as it might be in preventing discrimination in the workplace. This has been the case even in countries where legislation has made it mandatory for employers to demonstrate that a specific proportion of their workforce have a registered disability. Employers could fulfil such quotas by employing people with physical disabilities alone, or might even be willing to pay any fine rather than employ people registered as being disabled because of mental health problems²¹.

The social protection system may inadvertently act as a barrier to employment

Another key reason for the low rates of employment in some countries may be the way in which social welfare systems operate. An individual may be financially better off staying on benefits rather than returning to work. Disability benefits can be greater than unemployment benefits which may encourage individuals to withdraw from the labour market. Moreover, in order to gain access to some specialist support services in some countries it is necessary to be registered as disabled. In some instances the receipt of the highest level of disability benefits may legally prevent individuals from seeking work, as in Bulgaria²² and other Eastern European countries²³.

A lack of flexibility and heavy bureaucracy can also discourage individuals from seeking work. They may worry that if they obtain and then subsequently lose a job, that there may be substantial delays before being able to reclaim benefits, which might cause significant financial hardship²⁴. For the same reason health care professionals may also discourage their patients from seeking work.

I would include here the resistance of mental health professionals to encourage and support their clients to seek employment. Apart from the doubts these people have anyway, the mental health professionals are probably one of the first hurdles to overcome in the job seeking process.

What works to promote employment?

Supported employment initiatives

There is strong evidence that the most effective way of helping individuals obtain and maintain employment is through the use of Individual Placement and Support (IPS) interventions which seek to place individuals directly into open employment as soon as possible and then subsequently provide them with support from employment advisors (also known as job coaches) for as long as necessary. Longstanding evidence from outside Europe indicates that these schemes appear to be both more effective and cost effective than the use of traditional vocational rehabilitation schemes where individuals receive training within a sheltered environment, prior to seeking any employment²⁵. The six country EC-funded EQOLISE study provides evidence that the approach can also work in a European context. It suggested that IPS doubles access to work of people with psychotic illnesses, without any evidence of increased relapse (See Box). However, its effectiveness is not independent of external circumstances, particularly local unemployment rates²⁶
²⁷.

The context and way in which supported employment schemes are implemented will also be critical to their success. One scheme evaluated in the Netherlands did not appear to have a major impact on employment rates, but this was in part due to a lack of employment specialists involved in implementing the schemes, challenges in funding projects that crossed the health/labour policy divide, and problems in managing the schemes. Facilitators identified included better integration of supported employment schemes into mental health teams²⁸. Another recent study in London also highlighted the importance of integration with mental health services and the disincentives to take up employment due to inflexibility in the benefits system²⁹.

Support for social firms

Social firms, organised by people with mental health needs, can also play an important role in the recovery process and in encouraging participation in employment. They can benefit from public sector advice and seed funding to help kick start their activities. Successful social firms can again reduce the reliance that individuals have on social welfare benefits. Potentially they can help individuals develop new skills and build up their self-esteem and confidence³⁰.

Promoting awareness of disability and anti-discrimination legislation

Action can be taken to help employers, especially small organisations and those without a human resources department, to increase awareness of relevant disability and anti discrimination laws. It is also important that trade unions and employee organisations are aware of these requirements so that they understand and do not resent more flexible working conditions that may be given to people with mental health problems³¹.

Social protection system rules can be tailored to needs of people with mental health problems

More flexibility can be built into social protection systems to help encourage individuals to seek work if they so wish, whilst at the same time ensuring that they can reclaim benefits quickly if required. Legislation that prohibits individuals in receipt of a disability benefit from seeking work should be repealed. Equally individuals should be able to take on part time work without fear of having all their additional wages deducted from any benefit they receive. This would remove the disincentive to take up part time work as a route back to full time employment.

Reform of benefits, as in England, where individuals can now regain their benefits rapidly if employment does not work out can help encourage individuals to become more active jobseekers. This is one element of the 'Pathways to Work' approach introduced by the last UK government. This scheme included interviews with employment so-called specialists to provide advice and support as part of a process of helping return individuals to employment. Subsequently it included voluntary cognitive/educational health programmes to help people manage their condition (Condition Management Programmes) which have reported good results for people with mental health problems³². The Condition Management Programme may be appropriate for people with common mental disorders (interestingly enough the authors do not clarify what kind of mental health condition the people included in the study had), but not for people with severe and enduring mental health problems³².

Employment service staff can be trained to better understand needs

Public employment services across Europe have a critical role to play, both in helping jobseekers with mental health needs, and also supporting employers. Personalised assessment of needs either directly by public employment services, or contracted to specialist employment advisors is an important step which can also increase chances of an individual obtaining employment³³.

The use of activation mechanisms in the labour market

The existence of activation mechanisms in labour market policies across Europe is increasing. These combine a range of regulatory measures and economic incentives for individuals and employers. Relatively high rates of employment for people with mental health needs in Denmark may in part be due both to the promotion of flexible regulations on benefits and the promotion of active labour market inclusion policies³⁴.

Governments can help incentivise companies to take on people with mental health needs, not only through the provision of advice, but also through financial support. Public sector support is particularly important in the case of small and medium size enterprises that are the most common source of private sector employment in Europe. In some countries, Germany and Portugal for

example, employers may receive a tax rebate if they employ an individual with a disability. In other countries, grants are available to adapt workplaces to make them more amenable to people with disabilities. There might also be rewards for good practice, for instance rating or benchmarking companies in terms of the inclusivity of their recruitment practices.

Leading by example: the role of public sector employers

The public sector is a major employer in all EU countries. It can lead by example, through demonstrating that it has inclusive recruitment practices. It can also help to promote awareness of the important expertise and insights that individuals with mental health problems can bring. For instance, public health and social care organisation might explicitly hire people who have lived with mental health problems in order to work within community mental health or supported employment teams.

Shifting more of the focus to tackling discrimination rather than just stigmatisation

Discrimination may be easier to identify than stigmatisation; moreover legislation is in place to tackle discrimination regardless of individual attitudes which are more difficult to change. The extent to which employers are recruiting people with mental health needs may be monitored; legal proceedings may be taken in situations where discrimination can be identified. The adverse publicity alone of any legal case may act as a spur to an employer to adopt inclusive recruitment practices.

One potential way of addressing concerns over disclosure of health status may be for EU Member States to build on experience from the US where any pre-employment questionnaire can only ask about health status where it is directly relevant to the job in question³⁵. There are also opportunities to share experiences between different countries on how successful legislation has been in reducing discrimination against people with mental health problems and what might this mean for the drafting and implementation of new legislation.

Examples of policy and stakeholder initiatives

- Practical assistance to managers to support employees with mental health problems

BOX A: England: 'Working it Out': A Resource for Employers

Working it Out is a comprehensive resource pack launched in September 2010 designed to help raise awareness of mental health conditions in the workplace and provide employers with practical advice and guidance on how best to support and manage a member of staff should they become unwell.

It was produced by SHIFT – an initiative to tackle stigma and discrimination surrounding mental health issues in England. Its aim is to create a society where people who experience mental health problems enjoy the same rights and opportunities as other people.

The DVD, free to employers and organisations based in England, includes a brand new set of short employment films with accompanying training notes and other resources. Five short films show employees recounting their real-life experiences of mental health conditions within the workplace, mixed with dramatic reconstructions. The films also feature managers who describe how they effectively managed and supported their staff using best practice approaches.

<http://shift.org.uk/employers/workingitout/>

Why it matters: Employers need to have better awareness of the needs and positive experiences of people with mental health needs in the workplace. Training and support for employers can help facilitate the greater participation of people with mental health problems in the workforce.

- Individual Placement and Support (IPS)

BOX B: European IPS scheme (ref 26)

Under the European project EQOLISE (please see the box on European projects below), individuals with severe mental health problems in six European countries were randomly allocated to IPS or conventional vocational rehabilitation services. Over the 18 month study period the average number of days working in competitive employment in the IPS group was 130 compared with 31 in the vocational service group. 55% of people in the IPS group worked at least one day in competitive employment compared with 28% in the vocational service group. Time spent in hospital in the IPS group was half that in the vocational service group.

Why it matters: This project demonstrates IPS can work in very different European contexts. It can help individuals with mental health problems return to work more quickly than would otherwise be the case. They benefit from jobs obtained on the open employment market paying a competitive wage, whilst continuing to receive support. If well implemented, it can potentially improve long-term participation in employment and avoid some costs to social welfare and health care systems.

- Social enterprise building on positive characteristics

BOX C: Denmark and Scotland : Active inclusion of people with autistic spectrum disorders in information technology company

In 2004 Specialisterne was founded as the first company in the world to base its business model on employing people with Autism Spectrum Disorders (ASD). It now employs more than 40 people with these conditions. The company states that its '*vision is to give individuals with autism an opportunity to be seen as valuable and worthy members of the society. We use the characteristics of autism in a positive way, we provide valuable services for the corporate sector on market terms.*'

Since 2004 they have provided assessment and training for 155 individuals with ASD. After a 3-5 month long individual assessment strengths, weaknesses, special aptitudes, capabilities and interests are characterised and needs for support, guidance and environmental adjustments to perform in a job situation determined. 40% of these assessment activities have resulted in employment as consultants with the company. It now has more than 40 consultants.

In August 2010, with support from Community Enterprise Scotland (CEiS), Specialisterne Scotland has now been set up in Glasgow. CEiS chief executive Gerry Higgins has stated that 'by 2015 we expect to employ a total of 61 people, 50 of whom will have autism and have a projected turnover of £1.6m.' As a social enterprise, will re-invest any profit to help create jobs for people with ASD.

<http://www.specialisterne.dk/english/>

Why it matters: Specialisterne demonstrates that there is both a business case and sustainable social enterprise model when employing people with mental health needs can also help counter some stigma and discrimination in employment.

- Training programmes to promote return to work

Box D: Czech Republic: Green Doors Training Cafés

Green Doors is a not for profit organisation operating in Prague. It aims to promote the integration of people with mental health needs into all aspects of society and to promote a change in the public perception of mental illness through a range of public events.

The organisation has three Training Cafés that provide vocational rehabilitation. One provides intense vocational training in an environment similar to regular employment conditions on the open market. Occupational therapists and social workers support the clients during training. The goal is to improve support a return to the open job market. The project reports that between 60% and 70% of clients eventually return to open employment.

<http://www.greendoors.cz/english>

Why it matters: It is important that different sectors including social welfare, health and employment work together to help facilitate a return to work. Not for profit organisations can play a key role in delivering services.

- Building on lived experience in work training

Box E: The Ex-IN project: Harnessing the lived experience of people with mental health needs in work

EX-IN (EXperienced INVolvement) is a pilot project funded by the European Leonardo da Vinci Programme. The project aims at the qualification of people with lived experiences in mental health distress to work as supporters in mental health services or as trainers for mental health professionals. Mental health professionals and trainers from six European countries are working together to develop a specific training which is focused on the experiences of the participants.

<http://www.ex-in.info/>

Why it matters: People with experience in living with mental health problems have key skills and insights which they can utilise through paid employment in mental health services.

EU Projects

EMILIA: Empowerment of Mental Health Service Users

The EMILIA project was a Framework 6 Research Project that will conclude in January 2011. The EMILIA project explored the use of lifelong learning as a means of achieving improved social inclusion of mental health service users with enduring, long term mental health difficulties. The aim of the study was to improve the way in which service users can experience greater participation and inclusion either in the delivery of services or in education and training delivery in meaningful ways which is intended to include greater social inclusion, and paid employment, however locally defined.

16 partners in 12 EU countries took part in the study, the initial results of which were presented

at a final conference on Lifelong Learning and Mental Health in Paris this year.

The conference documents are available at <http://www.lifelonglearninginmentalhealth.net/>

Further information on the EMILIA study is available from <http://www.emiliaproject.net/>

A further project, Promoting Mental Health Minimising Mental Illness and Integrating through Education (PROMISE), has been co-funded by the Public Health Programme 2009-13. It will build on EMILIA and other project outcomes in involving service user groups across Europe in the design and delivery of mental health training for professionals. It will develop and disseminate guidelines for generic training and education with respect to Mental Health Promotion and Illness Reduction, and in addition specific applications with respect to the prevention of suicide, depression, and alcohol and drug abuse.

Further information about PROMISE is available by contacting Chris Griffiths at C.Griffiths@mdx.ac.uk

EQOLISE

EQOLISE (Enhancing the Quality of Life and Independence of persons disabled by severe mental illness through Supported Employment) was a 3-year project led by a team at St George's Medical School in London.

The goal of the project was to run a randomised controlled trial of a supported employment intervention based on an American model for supported employment for those with severe mental health problems. This 'Individualised Placement and Support' (IPS) model recommends the 'place and support' of people with mental health problems rather than the more traditional 'support and place' of sheltered employment. The IPS model was trialled versus high-quality train-and-place vocational rehabilitation in six European centres.³⁶

IPS was more effective than the Vocational Services for all vocational outcomes. 54.5% of the IPS patients (N=85) worked for at least one day compared to 27.6% of the Vocational Service patients (N=436). They were significantly less likely to be re-hospitalised. Local unemployment rates explained a significant amount of the variation in IPS effectiveness and both national economic growth and welfare systems influenced overall employment rates in both services. IPS doubles the access to work of people with psychotic illnesses, without any evidence of increased relapse.³⁷

This 'Evidence Based Supported Employment' model has now been adopted in several European Member States as the method of choice for supporting people with severe mental health problems into work. This project enabled links to be made between Europe and the US in this field, links which continue to yield good results.

The results of the project have been widely published in the literature.³⁸

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4. RIGHTS, RESPONSIBILITY AND CITIZENSHIP: SAFEGUARDING THE RIGHTS OF PEOPLE AFFECTED BY MENTAL ILLNESS

Invited author: Hans-Joachim Salize (Central Institute of Mental Health, Mannheim, Germany)

Key messages

- People with mental health problems and their relatives should be empowered and enabled to execute their fundamental rights as citizens, as well their human rights in relation to care and treatment.
- People with mental illnesses are at greater risk than the general population of certain physical illnesses, such as obesity, diabetes and cardiovascular disease, and yet they are less likely to be diagnosed or treated for these diseases.
- Societies must strengthen their efforts to overcome legal, administrative, societal, economic or other barriers that prevent people with mental health problems from enjoying full and equal participation.
- Restriction of the rights, liberties and choices of people with mental health problems, in relation to care and treatment or legal capacity, because of their need for treatment or public safety concerns, should be undertaken with extreme caution and following the principle of least restrictive option. Compulsory treatment should be subject to rigorous legal scrutiny regarding its medical appropriateness and adherence to national and international law.

The Problem

- The rights of people affected by mental illness are infringed

Decades after the widespread shift to diversified community mental health care, discrimination against and marginalisation of persons with mental ill health or a history of mental disorder is still widespread across Europe. Discrimination can occur in many domains of life, such as health care, social care, housing or employment and may be sanctioned in many ways, directly or indirectly by fellow citizens, public authorities, legal frameworks, health care services, social welfare offices or others. People affected by mental illness should be able to enjoy the same rights as others, in health and social care facilities and outside. They should be able to take part as active European citizens, individually, in their community and as part of wider society.

- Infringement of medical rights contributes to increased mortality and risk of social disadvantage

People with mental illnesses are at greater risk than the general population of certain physical illnesses, such as obesity, diabetes and cardiovascular disease, and yet they are less likely to be diagnosed or treated for these diseases. While care of these physical illnesses is improving for the general population, it has decreased for people with a mental illness. This inequality in the diagnosis and care of their physical health problems contributes to the 25-30 years shorter life expectancy of people with a severe mental illness^{1,2}.

Poor or inequitable health insurance coverage, administrative barriers to social security or welfare programs affect persons with mental health problems above average, multiplying their risk for unemployment, neglect, marginalization, insufficient health care, social decline or even homelessness.

- Public health care service capacity is insufficient to cope with global changes

Economic crises, armed conflicts, migration or globalisation processes increase the prevalence of psychological distress or mental health problems among groups such as refugees, voluntary migrants or ethnic minorities. The adaptation of public or health care services of host societies to optimize their appropriateness towards the specific mental health needs and the linguistic and historical traditions of such groups is deficient.

- Basic rights of citizenship and approaches to compulsory treatment are variable across Europe

The right to political participation is a fundamental human right and legally protected by the Universal Declaration of Human Rights or the Charter of Fundamental Rights of the European Union. The ability to vote and to stand for election is at the heart of citizenship. The potential for people with mental health problems to participate in the democratic process varies across Europe. Although any measure of protection, as applied to persons with mental health problems, should not automatically deprive a person of the right to vote, numerous EU-Member States suspend the exercise of that right in cases of legal incapacity or during detention, guardianship or other measures, regardless of the actual level of functional ability of the person concerned.

It is internationally agreed that any compulsory measure to a mentally ill person is an intervention of last resort and only to be applied in an acute crisis or state of emergency. However, the legal criteria for involuntary placement in psychiatric facilities differ widely across Europe.

Most legal frameworks of European countries include the basic right of appeal to a court against an involuntary placement or coercive treatment. However, few national laws obligatory stipulate or regulate the inclusion of an independent legal representative, counsel or advocate of involuntarily placed persons into hearings or trials. Furthermore, only a minority of countries provide legal support to involuntarily placed persons free of charge.¹

- Psychiatric and forensic sectors are interlocking and require close collaborative management

More restrictive practices in general psychiatry may support a tendency to marginalize or discriminate mentally disordered persons when inappropriately shifting them to forensic psychiatric services or penitentiaries. These sectors should be seen as interlocked systems, where changes in legal framework or routine practice in one sector may considerably affect admission rates and conditions in others.³

- Experts by experience are under-used in planning.

The attitudes and expertise of users of mental health services or persons having experienced any form of coercive psychiatric treatment is not adequately used for planning purposes or decision making in the field. The drafting of mental health laws or other decisive processes lacks deep patient- or consumer organisations involvement.

- Research is still lacking and could be re-directed.

The resources for research on the rights, the discrimination or participation or good care of persons with mental health problems must be improved. While results from studies on these issues may directly improve the situation of persons concerned, findings from much better funded neurobiological research on the causes of mental disorders - although also important - usually take much longer to be developed to field-ready treatments.

What works

- *Promotion of citizenship and empowerment*

The concept of citizenship in the mental health field is constituted as a solution to the issues of exclusion, discrimination, and poverty often endured by persons with mental problems or disorders. It is a multifaceted concept interfering in many societal fields. Promoting this concept requires adequate agencies and funding. *Community based mental health care services* are providing core mental health services to full capacity in most countries. To assign them with mental health promotion or similar tasks connected to a population based public mental health approach without sufficient additional funds, staffing or training would risk erosion to their considerable achievements. *Consumer operated services organisations* or self help agencies are non-profit organisations, usually run by people with mental disorders that provide peer support and a range of other non-clinical services to people with mental illnesses. Often they contribute essential services left open by the professional care system. Being membership organizations with democratic norms and strongly tied to local communities, these organisations may be seen as locus of empowerment and citizenship and should be strengthened.⁴

- *Legislative measures*

The implementation of legislative provisions promoting and safeguarding the rights of persons with mental health problems must be intensified and - in the margins of sovereign national legal frameworks - internationally homogenised.

Legal regulations must address and balance the need for and right to treatment of such persons, the requirements for public safety and the inevitable infringement of autonomy, freedom, dignity or basic human rights coming along with involuntary measures. Crucial is the regulation of compulsory treatment of persons suffering from mental disorder who are lacking insight and/or are putting immediate serious threat to themselves or others. These criteria should always be evidence based and correspond to the quality standards in mental health care.

Regular evaluation of national legal frameworks and mental health legislation is needed to keep pace with new developments and achievements in psychiatric treatment and care and the prevention of mental ill health.

A close collaboration of the Legal or Criminal Justice System and Mental Health System is beneficial when shaping new laws or adapting legal frameworks. Consumers' perspectives and expertise must be also included into mental health policy processes and decision making. Provisions must be made enabling persons with mental health problems good access to information on their rights and support.

- *Information Systems and new promising initiatives*

National and European data reporting and information systems must be extended and standardized to reflect the rights and its violation and other crucial issues of persons with mental health problems. For regular and valid information on the size of the problem, indicators on coercive placement and treatment of persons with mental health problems must be added to European reporting systems (compulsory admission or detention rates, mental ill health in prisons, forensic cases etc.).

New techniques or concepts with a potential to balancing the contradictory values tied to the issue must be developed further (e.g. new risk assessment techniques, involuntary outpatient

commitment, psychiatric advance directives etc.). Their potential as less restrictive options to involuntary placement or treatment must be evaluated by research.

Examples of Policy and stakeholder initiatives

- Bring initiatives and implementation in line with the UN CRPD:

Box A. UN Convention on the Rights of Disabled People (CRPD) and Mental Health Declaration for Europe

The UN Convention on the Rights of Disabled People⁵ and the Mental Health Declaration for Europe⁶ provide the basic rules and guidelines for promoting citizenship and fighting the violation of rights of persons with mental health problems in Europe. They have been adopted, cited, reaffirmed or commented upon in numerous documents, recommendations or reports in Europe and worldwide.

Why this matters: *The CRPD is an international human rights treaty that is legally binding on those who have ratified it in its entirety, including the European Community and numerous member states. It supersedes conflicting national laws; It included mental ill health as a cause for disability.*

Box B. Mental Disability Advocacy Centre (MDAC)

In collaboration with Hungarian NGOs, the Mental Disability Advocacy Centre (MDAC) has published a shadow report which looks in detail at the level of the UN Charter on the Rights of Disabled People (CRPD) implementation in the country⁷. The report was launched in August 2010 and contains recommendations to the Hungarian government, including providing supported decision-making for the approximately 80,000 Hungarian people under guardianship; amending legislation to guarantee reasonable accommodation and accessibility; how to close large institutions and develop independent living; how to ensure inclusive education of children with disabilities and how to bring employment law in line with the CRPD. A similar report is announced for Croatia in early 2011.

Why this matters: *MDAC is an international NGO working solely on the rights agenda for people with mental health problems.*

- Assistance for basic rights of citizenship:

Box C. Disability Act, Denmark

In 2009 Denmark amended its Act on Parliament, Regional and European Elections so that persons with disabilities now have the right to designate a person of their choice to assist them when voting⁸.

Why this matters: *As work by the Fundamental Rights Agency shows, access to democratic participation by people with mental health problems varies across Europe. Activities to include disabled people in elections are welcome.*

- Local self-help and advocacy:

Box D.

GEM, France

The development of around 300 self-help groups in France is supported by a specific public fund from the French Government. Managed by users and carers' organisations, these groups are seen as a new tool and perfect opportunity to enhancing social inclusion, fighting stigma and supporting empowerment.

Irish Advocacy Network, Ireland

Relevant initiative on advocacy in mental health

<http://www.irishadvocacynetwork.com>

Why this matters: *Community led mental health services assist with local community participation by people with mental health problems. Widespread adoption of self-help/support or advocacy organisations enables the voice of people with mental health problems to be heard at local level.*

- International collaboration and networking for mental health care and rights issues:

Box E. International Mental Health Collaborating Network - Charter of Purpose and Action

The IMHCN Charter sets out the purposes of what the network believes is necessary to achieve a Whole Life for users, for them to obtain full citizenship free from stigma and to fight for social inclusion for themselves. It is a campaigning and advocacy agenda for human rights and to fulfil our mission in promoting community mental health services that better meet the needs of service users.

It also calls for action from Governments, policy makers and service providers, professionals, managers, users and carers.

The charter has at its core a fundamental belief in the values and principles that should be applied to any mental health service and professional practice. The charter has 7 core Articles that set out the purpose and some actions of what is required by organizations to achieve these.

Members of the IMHCN have experience in applying these articles in community mental health service design and development.

More information can be found online at: <http://www.imhcn.org/charter>

Why this matters: *IMHCN is an international network of recovery-oriented practitioners, and similarly to ESN, can play a role in disseminating and incubating good practice.*

EU Initiatives

Council of Europe Recommendations

The Council of Europe has devoted two specific “Recommendations of the Committee of Ministers to member states” to the “Protection of the Human Rights and Dignity of Persons with Mental Disorders”: Rec (2004)10 and Rec (2009)3. Rec (2009)10 provides a monitoring “checklist” and recommends that the governments of member states use it “as the basis for the development of monitoring tools to assist in determining their level of compliance with Rec (2004)10”

The checklist is divided into eight topics which are called “principles”. For each principle several concrete “questions/indicators” are formulated, for example “Is discrimination prohibited by law?” Altogether nearly 150 such “questions/indicators” are formulated under 8 principles, such as non-discrimination, civil and political rights or the protection of vulnerable persons.

The practical nature of the checklist, its richness and comprehensiveness constitute an essential source of action for all those who are involved in protecting the dignity and human rights of persons with mental disorder and in ensuring appropriate care for them.

For details see:

[https://wcd.coe.int/ViewDoc.jsp?Ref=Rec\(2004\)10&Language=lanEnglish&Site=CM&BackColorInternet=9999CC&BackColorIntranet=FFBB55&BackColorLogged=FFAC75](https://wcd.coe.int/ViewDoc.jsp?Ref=Rec(2004)10&Language=lanEnglish&Site=CM&BackColorInternet=9999CC&BackColorIntranet=FFBB55&BackColorLogged=FFAC75)

Other Recommendations issued by of the Council of Europe include:

- the Recommendation of the Parliamentary Assembly on psychiatry and human rights (Recommendation 1235 (1994))
- the Recommendation to Member States concerning the ethical and organisational aspects of health care in prison (Recommendation No R 98)
- the Recommendation to Member States on European Prison Rules (Recommendation Rec (2006)2)

Additional initiatives of particular relevance:

- The *new Anti-Discrimination Directive*, which is backed by the European Parliament and put forward by the European Commission, is intended to reduce discrimination on grounds of religion or belief, age, disability or sexual orientation, whether direct or indirect, and whether based on real or presumed criteria.
- The *EU Proposal “Interpretation and translation in criminal proceedings”*, Directorate General Justice, Freedom and Security, will come into effect in 2012. It guarantees every EU citizen equal access to interpretation and translation during criminal proceedings. It is likely to improve the situation of foreign-language mentally ill offenders or mentally disordered members of ethnic minority groups suspected or accused of a crime or involved into court hearings as they would be entitled to get access to interpreters or translators.

EU Projects

Institutional Treatment, Human Rights and Care Assessment (ITHACA)⁹

ITHACA is a project funded under the Public Health Programme (2007-2010). Fifteen partners are led by the Institute of Psychiatry. A key deliverable of the project is a European Toolkit to monitor Human Rights and General Health Care in Mental Health Facilities

The ITHACA Toolkit provides a clear and practical way to monitor human rights and general health care in mental health facilities. The Toolkit was designed by services users, human rights experts, psychiatrists, psychologists and social scientists. It has been successfully field tested in 87 sites across 15 countries, covering a wide range of mental health care settings and can identify both human rights violations and examples of good practice in protecting, respecting and fulfilling the rights of persons with mental disabilities.

The ITHACA Toolkit is already available in English and will be shortly available in the following languages: Bulgarian, Czech, Dutch, English, Finnish, German, Greek, Italian, Hungarian, Lithuanian, Romanian, Slovak, and Turkish.

For full details of the ITHACA Toolkit visit: „<http://www.ithaca-study.eu/>

The Fundamental Rights Agency

The EU Fundamental Rights agency is mid-way through a 34 month project that aims to better understand how the fundamental rights of persons with mental health problems and persons with intellectual disabilities are safeguarded in the EU and where violations of rights occur. The project clearly recognises that people with intellectual disabilities and persons with mental health problems are two distinct groups of individuals, but that stigma is the common reaction to both, which consequently leads to social exclusion and discrimination. This project was inspired by the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and Optional Protocol.

In particular, the Fundamental Rights agency has set out to:

- Conduct comprehensive legal research on national and international legal frameworks available to persons with intellectual disabilities and persons with mental health problems;
- Examine the situation of persons with lived experience of intellectual disability or mental health problems;
- Mobilise a network of organisations and individuals dealing with fundamental rights aspects of intellectual disability and mental health problems.

Outcomes of the project will be available online in the coming months. Already preliminary results of a survey on the right to political participation of persons with intellectual disabilities and persons with mental health problems in the EU is available at: http://www.fra.europa.eu/fraWebsite/research/projects/proj_disability_en.htm

Compulsory Admission Study

A series of studies funded by DG Health and Consumers of the European Commission explored the situation in Member States regarding the legal frameworks and epidemiology of compulsory admission to psychiatric hospitals, to forensic psychiatric treatment and the situation of mentally disordered prison inmates^{1, 3, 10, 11}. The compulsory admission study analysed considerable differences in regulations for and practices of admitting mentally disordered persons involuntarily to psychiatric treatment and huge differences in the

proportion of involuntary treatment episodes across Europe. The study on forensic services for mentally disordered offenders showed a remarkable shortage of evidence in this much debated field, given the high level of public awareness and relevance for public safety of the issue.

Prevalence and incidence rates on mentally disordered persons placed or treated under legal forensic regimes vary remarkably across Europe within a pan-European trend to constantly rising rates from 1990 onwards. The EUPRIS-study on mental disorders in prisons identified an extreme knowledge gap on the amount of mental ill health in the European prison systems. Only a small minority of European countries provide regular national statistics on the frequency of mental disorders of prisoners or on the availability of psychiatric treatments for inmates. Diagnostic procedures, release planning and psychiatric after-care for mentally disordered inmates are extremely deficient, increasing significantly the risk for relapsing and re-offending after release.

EUNOMIA

In the same context, the EUNOMIA-study¹², funded from 2002 to 2006 by the Research Directorate General of the European Commission in its Quality of Life and Management of Living Resources Programme focussed on the legal frameworks and the varying practices of coercive treatments of mentally ill persons across European Union Member States. The assessment included also the attitudes of family members and relatives of patients towards coercive treatments.

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5. COMPREHENSIVE HEALTH AND SOCIAL SUPPORT FOR PEOPLE WITH MENTAL HEALTH PROBLEMS

Invited authors: Nicolas Daumerie and Aude Caria (WHO-CC, Lille, France)

Key messages

- The availability of accessible primary care mental health services is a precondition to the social inclusion of people with mental health problems. Holistic community-based health services should be age and gender appropriate and delivered as part of a community partnership which includes government, civil society and social protection services.
- People with mental health problems and their relatives/carers have to be involved as equal in all service delivery aspects including, inter alia, services design, implementation, management and evaluation.
- Because experience of mental illness is itself a risk factor for certain physical illnesses and for inequalities, a Public Mental Health Plan with a whole system approach for recovery and empowerment should be developed, and, more importantly, delivered.
- The provision of safe, evidence-based care, delivered in partnership with users, must be maintained even throughout cuts in public spending. Addressing mental ill health and the knock-on effects of it delivers substantial savings across a range of policy areas.

The problem

- Access to adequate service and treatment remains difficult

Inadequate and inappropriate mental health systems and services are a major cause of poor mental health outcomes¹. Neuropsychiatric disorders are the second greatest cause of the burden of disease on the European Region after cardiovascular diseases². They account for 19.5% of all disability-adjusted life-years³ (DALYs). Key facts are: 20-30% of global population has mental health problems each year⁴ but around 2/3 of people receive no treatment^{5, 6}. By comparison only 8% of people suffering from type 2 diabetes mellitus in Europe receive no care⁷. Two main issues about accessibility of services can be considered: financial⁸ (national social security system – budget allocation) and geographical.

- Institutional Psychiatric care still dominates

In a quarter of European countries (WHO Euro region), mental health services are not available in the community. In some countries, over 50% of all users are treated in large mental hospitals. Two thirds of all “beds” in Europe are located in psychiatric hospitals⁹. Very often, more than 80% of the money devoted to mental health is spent on maintaining large institutions. All European countries (WHO Euro region) must work with limited resources,

their mental health budgets constitute on average only 5.8% (ranging from 0.1% to 12%) of their total health expenditure. A large proportion of these budgets is allocated to services, and only negligible amounts invested in promotion and prevention¹⁰.

The central role of GPs and others primary actors in mental health is well known but recommendations have not yet been uniformly applied. There is very few national policy for community based care development. Children experiencing mental health problems are especially at risk of being separated from their families and institutionalized - "eluded". They have zero capacity to advocate for their rights¹¹.

- Human resources and training in community mental health, recovery approach and empowerment models are scarcely developed

The dominant cultural model of professionals for mental health care is hospital focused, and therefore hampers the development of Community mental health models. Human resources are still concentrated in psychiatric wards and in scarce supply in the community.

Many mental health professionals are not adequately trained to provide the necessary services: community-based care, recovery-oriented treatment and care, prevention programmes, assessment, network management, coordination of care, mental health information, training/education and therapies. Natural partners in the community (GPs, social and educational actors, justice, police, media workers) lack information about mental health issues and the care system.

Mental health human resources show significant variations between countries.

- Lack of Community based system results in inequalities, stigma, and discrimination

People with mental health problems are at high risk of social exclusion¹². Mental health is often both a cause and a consequence of poverty, compromised education, vulnerability, difficulty accessing housing, health care and employment, and lack of access to welfare, social security, and community public services. The stigma attached to mental health problems jeopardizes the development and implementation of mental health policy including social inclusion. Stigma is one of the main causes of discrimination; it affects people and relatives, limits social inclusion and networks. It contributes to the abuse of human rights in some large institutions and most of societies¹³. Many live in housing or institutions identified with mental illness, and therefore avoided by members of communities¹⁴. In addition, the negative consequences of mental disorders can result in disabilities, including self imposed stigma and discrimination¹⁵.

- Citizens (users, carers or other lay persons) often are not involved or do not get involved in projects dedicated to mental health

People with lived experience of mental distress are often not considered key partners in the delivery, design, monitoring and evaluation of policies, promotion and prevention interventions, training, research and services. Information is not accessible for every stakeholder, user and carer. Independent systems of monitoring and evaluation of mental health services, including evaluation and monitoring of the rights of service users, are

underdeveloped. The involvement of European citizens (users, carers, professionals or not) in mental health policy issues at each level (from governmental to local) is a crucial goal.

What works

- *Access to adequate care is improved by financial and geographical solutions*

Strong laws, policies and governance for comprehensive care development including social insertion have to be promoted^{16, 17}. Access to care is improved when community care is founded on local structures and systems that integrate health services across specialties with social systems and community organisations. Effective community mental health services do not consist of isolated and disconnected initiatives, but should rather aim to provide continuity and coordination of care and treatment for users, in a defined population and based on need and resources. Key principles are described below. Accessible, affordable and acceptable care requires mental health systems and services that take into account local culture, available resources and a pyramid of services providing an optimal mix of level of care and services¹⁸.

- *Stepped care and a spectrum of services*

Given the heterogeneous courses of mental illnesses it is of importance to flexibly tailor treatment to the individual needs of the service user, i.e. to select the appropriate form and intensity of care from an available spectrum of interventions taking into account the user's current health status. The provision of treatment in a stepped care format promises an effective and efficient allocation of therapeutic resources. Monitoring systems (e.g. longitudinal assessment of symptoms and impairment) should be implemented that allow a) to identify the adequate level of care and b) to identify time points within an illness episode when a shift to more intense care (e.g. inpatient treatment following outpatient treatment) or less intense care (e.g. maintenance of treatment following intense psychotherapy) is indicated.

- *Community based mental health care is a precondition for social inclusion*

Care based in the community has been shown to offer a better quality life and greater satisfaction for service users and their relatives than traditional hospital care¹⁹. It should be conceived, planned and developed as a whole system with a community development approach building sustainable partnerships with local communities²⁰.

Care and treatment should be provided closer to the individual's home^{21,22}, in normal settings chosen by the person themselves and services must be accessible and available when and where the person needs it, that is, on a 24 hour / 7 day a week basis. Multi-disciplinary mobile teams for crisis²³, assertive care²⁴, and ambulatory care²⁵ are central to community based, recovery-oriented mental health services and systems.

- *Human resources and training have to move towards a new professional culture based on partnership with common values and language*

Community based services mean shifting human resources from big institutions to community, where care is delivered²⁶. Mental health staff training positively influences staff

attitudes and professional identity and skills in supporting the recovery pathway of mental health services users. Training in community care, prevention, assessment, network management, care coordination, psycho-education and therapies is essential. Information and common training with professionals from social, education, justice, police, media fields and local elected, enhance the ability of partners from each of these sectors to work together and to fight stigma (anti-stigma programmes and mental health awareness programmes in health/social workforces). Involvement of users and carers in mental health partners' training sessions and mental health services (peer-support) has improved the changes in professional thinking and promote the development of a new professional culture orientated on recovery and self-management instead of illness.

- *Comprehensive Intersectoral policy and practices decrease inequalities, stigma, and discrimination*

Providing comprehensive help and support to users unable them to continue or regain a whole life in all its domains, well-being, health, socially included, access to adapted housing, education, work, cultural and leisure activities, sports, etc. in ordinary locations. This cannot be achieved by the health service alone.

Developing Community whole systems based on collective responsibilities with an overall common purpose is the most viable way of decreasing inequalities and discrimination of people with mental health problems. This should be done by building intersectoral partnerships involving various local authorities (municipalities, locally elected mayors), community organisations, users, family members and business leaders.

- *Access to information, advocacy and human rights defence is a key to users' empowerment*

Promote sustainable citizenship is a fundamental factor for empowerment, recovery and tackling stigma/discrimination²⁷.

Programmes and actions aimed at strengthening users and carers' rights and empowerment show evidence of decreasing social exclusion. They should address the following fields: legislation (human rights, social rights, and work rights), access to care, health information and education about services and treatment, participation in planning and review of care financial support for users NGOs²⁸:

Examples of Policy and stakeholder initiatives

- Initiatives to increase access to adequate service and treatments

BOX A. Italy: National Law n°. 180 “Legge Basaglia”

The current Italian mental health legislation dates back to 1978 when two basic Laws were issued: Act n.180 specifically concerning mental health care (13 May) and Act n°.833 reforming the whole frame of care in the Country (23 December).

The central issues of both Acts, as far as mental health is concerned, can be described as follows:

- 1) Civil rights of mentally ill people are to be fully acknowledged

- 2) Psychiatric Hospitals must be gradually closed or differently utilised; no more patients can be admitted in those existing hospitals, and old residents should be moved to outpatients services or therapeutic communities
- 3) The whole system of treatment is based on a network of community oriented facilities
- 4) Treatment for acute problems is delivered in General Hospitals, in Wards named "Psychiatric Service for Diagnosis and Care" with a maximum of 15 beds
- 5) Compulsory treatments should be as limited as possible, both in number and in length. They should also be considered only as a first step in a treatment programme to be delivered in community services.

Why this matters: *this reform has been the first to be promoted in Europe, it has been backed by a social movement towards integrating and accepting people with mental health problems into the community, a fact which distinguishes this experience from any other deinstitutionalization and remains a major ingredient in its positive development*

BOX B. Portugal: "National mental health plan" 2007- 2016

A new National Mental Health Policy and Plan (2007-2016) has been developed with the following objectives:

- Ensure equal access to quality care for everyone with mental disorders in the country, including those belonging to especially vulnerable groups;
- Promote and protect the human rights of people with mental disorders;
- Reduce the impact of mental disorders and contribute to the promotion of the mental health of the population;
- Promote the decentralization of mental health services, so as to enable care provision closer to people's homes and to facilitate greater participation by communities, people with mental disorders and their families;
- Promote the integration of mental healthcare into the general health system, at the primary care level as well as in general hospitals, so as to ensure continuity of care and facilitate access and reduce institutionalization.

- Enhance professional shift from hospital to community

BOX C. International networking to support the changes: International Mental Health Collaborating Network – Mental Health and Citizenship (IMHCN)

1. International, Regional and National Conferences on Whole Life Whole Systems in Mental Health, Recover Concepts and Practice, Self determination and Recovery, Social Inclusion.
2. Twinning Convention Collaborations between European countries. These are agreements between mental health service providers to exchange knowledge and information on good practice, to develop projects together on progressing social inclusion initiatives, integrating mental health into primary health care, social enterprises, community whole systems development, less discriminating community based services, self determination and self help.
3. Study visits and exchange programs on alternatives to hospital based services, 24 hour community mental health centres, recovery programmes, community forensic services, services for people with dementia, social cooperatives, early intervention for people with psychosis, community child and adolescent services, whole life social inclusion initiatives, etc.

4. Workshops on the details of developing and implementing new initiatives on services, acute and crisis, day care, social enterprises, vocational training, housing schemes, community whole systems development.

5. Advising mental health and community organisations, on community mental health good practice, changing psychiatric institutions, promoting social inclusion, developing a Whole Life-Recovery Approach, developing a Whole Systems way of working with community organisations.

Examples of pilot sites for good practices community mental health services in Europe: Trieste (Italy), Oviedo (Spain), Lille Eastern Metropole (France), Lyngby (Denmark), Cavan Monaghan (Ireland).

All information: <http://www.imhcn.org>

Why this matters: *IMHCN is an international network of recovery-oriented practitioners, and similarly to ESN, can play a role in disseminating and incubating good practice.*

Box. D. WHOLE LIFE PROGRAM – Training programme with study tours UK

“Whole life” believed that if we are to truly improve the experience of those with mental health problems, then the answers will not lie in simply investing more money, recruiting more staff or developing ever more sophisticated service models and systems. They believe in the need to question many of the fundamental beliefs and ideas that underpin our current mental health systems and the approach of individual practitioners working within them. Some of the questions that need be asked include what we think about mental health, what we believe about mental illness and what we believe the responsibilities of the State, mental health services and individual professionals should be in relation to those with mental health problems.

This website brings together the thoughts and ideas of a range of people who have contributed to the work of the Whole Life programme over the last few years. Through the Whole Life programme we have worked with individuals from local areas across the East of England and in the South West to explore alternative ways to develop their local mental health care systems.

All Whole life resources including the Whole life DVD, the Whole life work book, a Whole life audio CD and Whole life posters are available free-of-charge, are 'down-loadable' and are designed to be photocopied. <http://www.wholelife.org.uk/>

Why this matters: *In order for our thinking about mental health and the role of mental health services to progress further, a completely new discourse is required, one that provides the platform for a more progressive, pioneering and open minded approach to supporting individuals with mental health problems to reach their full potential.*

- Initiatives to encourage self-help and self-management to favour recovery

Box E. Recovery Practice and peer-led services – (For example : Nottinghamshire and Hertfordshire NHS, UK)

Recovery practice requires service providers to have access to a recovery toolbox. The network will enable providers, consumers and significant others to have access to such a toolbox. This will be done through access to workbooks, training days, master-classes and online support. Within the network there are a number of workbooks to enable people to work through issues such as voices, self-harm and planning recovery.

- Nottinghamshire Healthcare NHS Trust *Involvement Team*: Positive -

<http://www.nottinghamshirehealthcare.nhs.uk/get-involved/involvement-team>

- Herefordshire Healthcare NHS Trust *Inspiring Lives* : <http://www.inspiringlives.org.uk/>

Box F. ADEB, Associação de Apoio aos Doentes Depressivos e Bipolares (Association for support of Depressive and Bipolar Patients)

Since 1991, ADEB has been run for depressive and bipolar patients and their relatives, in Portugal. Their main objective is Promoting information about mental health, education and psychosocial rehabilitation of these people, with about 3.000 associates, nation wide.

ADEB's activities include: An SOS Help Telephone line; Psychosocial Support Sessions; Psycho education groups (for patients and for their relatives); Self Help Groups; Support for teenagers with Unipolar and Bipolar diagnoses; Promotion of several activities as seminars, colloquy, psycho education sessions, in the community, schools, or other places; Distribution of technical information about unipolar and bipolar diseases to the community; Support to the Families of these people (Unipolar and Bipolar); Homecare; Social Occupational Forum; Professional Support and Orientation; Legal Advice; Food Aid (in cooperation with Banco Alimentar contra a Fome), a Portuguese NGO that provides food to those most in need.

The main goals are the promotion of mental health, increased awareness in the community, advocacy, and the search for strategies that allow a better quality of life for unipolar and bipolar patients. Over the past 20 years, partnerships and policies have been developed with other organisations trying to enlarge the impact of our intervention and to reach out to as many people as possible.

- Non-traditional and non-hierarchical care structures and approaches

Box G. Citizen psychiatry and community mental health in practice: the Mental Health Local Councils (France)

The golden rule of Citizen Psychiatry could be: don't only have partners but rather be a partner in the community. This form of community mental health is based on the principle that citizenship is a fundamental factor for recovery²⁹. Concretely, it means to think global but act local, one of the best practical tool developed to achieve Citizen psychiatry goals is the Mental Health Local Council.

The Mental Health Councils are a new tool aimed at gathering, on a given territory (i.e. a town or a group of municipalities), all partners involved in answering to Mental Health issues (health and social professionals, GPs and nurses, justice, education, police, users' and carers groups).

The Mayor, responsible for the well-being of its population, coordinates the Council, which seeks together to improve the coordination between all partners. It is becoming a major tool in the fight against stigmatisation (citizenship for everyone) and in favour of social inclusion.

WHO-CC (Lille, France) is in charge of the implementation and follow-up of 50 Mental Health Councils across France³⁰

Why this matters: *Developing Community whole systems based on collective responsibilities with an overall common purpose is the most viable way of decreasing inequalities and discrimination of people with mental health problems.*

Box H. France: National Mental Health week (NMHW)

The National Mental Health Week in France is an awareness-raising action based on a bottom-up organisation, including users, families, carers and municipalities. More than 400 events and actions are organised each year in March, involving a wide cooperation between users, carers, professionals, local elected, the media and the general population. It aims at opening the public debate on the Mental Health issues, promoting public information, raising awareness of stakeholders and local elected, encouraging people to seek for help, and fighting against stigma of people experiencing mental health problems.

List of events: www.unafam.org and www.psycom75.org

Why this matters: *It is a major tool to enhance the partnership around Mental Health issues at a local level (i.e. basis of the creation of Local Mental Health Councils, gathering users and carers' associations, professional from Health, Social, Education, Justice, Police fields and local elected.*

Box I. Scottish Recovery Network

The Scottish Recovery Network is a network organisation supported by the Scottish Government. Its role is to support and promote recovery oriented practice in health and social care in Scotland. Its aims are:

1. To raise awareness of recovery from mental health problems, in particular longer term problems.
2. To learn more about the recovery experience, and the factors which help and hinder it, and to share that learning.
3. To share ideas and encourage and support action nationally and locally for the promotion of recovery.

The network developed a Scottish Recovery Indicator³¹ to enable services to monitor the extent to which they promote recovery, and has supported the development of the role of Peer Support Worker³², where people with lived experience of mental ill health are employed by acute and community mental health services to assist people receiving treatment with self-help and self management.

<http://www.scottishrecovery.net>

Why this matters: *Recovery is difficult to put into practice because as a concept it changes, and is hard to define. SRN plays a role in managing and promoting debate, whilst developing tools and structures to enable systematic adoption of recovery in mainstream practice.*

EU Projects

PROSPECT (EUFAMI- Peer to peer training programme).

Prospect is an innovative European training initiative which opens up fresh perspectives for individuals with direct experience of mental illness, whether they be people with experience of mental illness themselves, their family and friends, or health and social care professionals.

Prospect is a result of a project funded under the EU Leonardo Programme in 2001-2004 and led by the **European Federation of Associations of Families of People with Mental Illness** (EUFAMI). It combines the input from sixteen partner organisations, as well as representatives of people with mental illness, family carers, and health and social care professionals from twelve European countries.

There are four training programmes:

- Training Programme for Family and Friends
- Training Programme for People with Self-Experience
- Training Programme for Health and Social Care Professionals
- Common Ground Module

Further information :

http://www.eufami.org/index.php?option=com_content&task=view&id=73&Itemid=98

Why this matters: *Involvement of users and carers in mental health partners training sessions and mental health services (peer-support) improve the changes in professional thinking and promote the development of a new professional culture orientated on recovery and self-management instead of illness.*

The WHO-EC Partnership Project on User Empowerment in Mental Health³³

The WHO and the European Commission co-funded this partnership project with the main objective to support Member States to improve their strategies and actions to empower people with mental health problems and their carers. The WHO-EC Partnership Project on User Empowerment in Mental Health (April 2008 to March 2011) comprises four components:

1. Identification of indicators and success and failure factors for user empowerment in mental health;
2. Identification of good practice in user empowerment;
3. Support of governments and local actors in creating an environment for user participation;
4. Promotion of the mainstreaming of good practice in user empowerment in mental health.

The project has been implemented jointly with the relevant WHO-networks and Commission expert groups. User and carer associations, NGOs, WHO EURO Collaborating Centres, and other experts in policy, services, human rights and social inclusion form part of the Advisory Group of this project. Project deliverables will be fed into existing WHO-networks and the Commission's expert meetings, and it will also be made available to wider communities.

Many examples of good practices regarding comprehensive health and social support for

people with mental health problems have been identified in the framework of this project.

All information: <http://www.euro.who.int/en/what-we-do/health-topics/diseases-and-conditions/mental-health/activities/empowerment-of-service-users-and-carers>.

Why this matters: *It will make key contributions to the implementation of the Helsinki Declaration and Action Plan for Mental Health and the EC's mental health agenda as reflected in the European Pact for Mental Health 2008.*

Development of a European Measure of Best Practice for People with Long Term Mental Illness in Institutional Care (DEMOBinc)

The DEMOBinc study (Development of a European Measure of Best Practice in institutions for people with longer term mental health problems) was a three year collaboration across ten European countries (UK, Germany, Spain, Bulgaria, the Czech Republic, Italy, Poland, The Netherlands, Greece and Portugal). The study was funded by the European Commission and sought to develop a toolkit which could assess the quality of care in longer term mental health facilities, both those based in hospital and in the community. The final product of the project is a web based tool called the Quality Indicator for Rehabilitative Care (QuIRC) which assesses the living conditions and care that a unit provides and the degree to which it promotes the human rights and social inclusion of its residents.

The QuIRC is a self-report tool completed by the unit manager. It uses a computerised algorithm to produce individualised, printed reports which detail the unit's performance on seven domains of care (living environment; therapeutic environment; treatments and interventions; promotion of service users' self-management and autonomy; promotion of service users' human rights; promotion of service users' contact with family and community/social inclusion; the degree of Recovery based practice). These are plotted on a radar chart and the results for similar units in the same country are also shown for comparison. Further text provides more detail about the results and the areas of care the unit could focus on to improve their results.

The QuIRC is available at: <http://www.quirc.eu/>

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Annex 1 - Sections of the European Pact for Mental Health and Well-being¹ on social inclusion and combating stigma.

The participants in the EU high-level conference “Together for Mental Health and Well-being, Brussels”, 13 June 2008, acknowledged the importance and relevance of mental health and well-being for the European Union, its Member States, stakeholders and citizens;

I – recognised the importance of population mental health and impact of mental health problems in European societies;

II – agreed that:

- There is a need for a decisive political step to make mental health and well-being a key priority.
- Action for mental health and well-being at EU-level needs to be developed by involving the relevant policy makers and stakeholders, including those from the health, education, social and justice sectors, social partners, as well as civil society organisations.
- People who have experienced mental health problems have valuable expertise and need to play an active role in planning and implementing actions.
- The mental health and well-being of citizens and groups, including all age groups, different genders, ethnic origins and socio-economic groups, needs to be promoted based on targeted interventions that take into account and are sensitive to the diversity of the European population.
- There is a need to improve the knowledge base on mental health: by collecting data on the state of mental health in the population and by commissioning research into the epidemiology, causes, determinants and implications of mental health and ill-health, and the possibilities for interventions and best practices in and outside the health and social sectors.

III - called for action in five priority areas, including:

V - Combating Stigma and Social Exclusion

Stigma and social exclusion are both risk factors and consequences of mental disorders, which may create major barriers to help-seeking and recovery.

Policy makers and stakeholders are invited to take action to combat stigma and social exclusion, including the following:

- Support anti-stigma campaigns and activities such as in the media, schools and at the workplace to promote the integration of people with mental disorders;
- Develop mental health services which are well integrated in the society, put the individual at the centre and operate in a way which avoids stigmatisation and exclusion;
- Promote active inclusion of people with mental health problems in society, including improvement of their access to appropriate employment, training and educational opportunities;
- Involve people with mental health problems and their families and carers in relevant policy and decision making processes.

¹ Available online at: http://ec.europa.eu/health/mental_health/docs/mhpact_en.pdf, accessed 25th October 2010.

Annex 2 – Sections of the European Parliament resolution of 19 February 2009 on Mental Health (2008/2209(INI)) on social inclusion and combating stigma.

The European Parliament,

...

1. Welcomes the European Pact on Mental Health and Well-Being and the recognition of mental health and well-being as a basic priority for action;
2. Firmly supports the invitation to cooperate and foster action between the EU institutions, the Member States, the regional and local authorities and the social partners on five priority areas for the promotion of the mental health and well-being of the population, including all age groups, and different genders, ethnic origins and socio-economic groups, combating stigma and social exclusion, strengthening preventive action and self-help and providing support and adequate treatment to people with mental health problems and to their families and carers; stresses that any such cooperation must fully comply with the principle of subsidiarity;

...

6. Considers that the emphasis should be on the prevention of mental ill-health through social intervention, with particular focus on the most vulnerable groups; stresses that, in cases where prevention is insufficient, non-discriminatory access to therapeutic treatment should be encouraged and facilitated and that people with mental health problems should have full access to information about innovative forms of treatment;

...

10. Calls on the Member States to adopt UN resolution 46/119 on 'the protection of persons with mental illness and the improvement of mental health care' drawn up by the United Nations Commission on Human Rights and adopted by the General Assembly of the United Nations in 1991;
11. Calls on the Member States to give people with mental health problems the right to equal, full and appropriate access to education, training and employment, in accordance with the principles of lifelong learning, and to ensure that they receive adequate support for their needs;
12. Stresses the need for clear and long-term planning for the provision of high-quality, effective, accessible and universal community and in-patient mental health services and for the adoption of criteria for monitoring by independent bodies; calls for better cooperation and communication between primary healthcare professionals and mental health professionals to deal effectively with problems associated with mental and physical health, by encouraging a holistic approach which takes into account the overall profile of individuals from the point of view of physical and mental health;

...

19. Calls on Member States to draw up up-to-date mental health legislation which is in line with international obligations as regards human rights – equality and the eradication of discrimination, the inviolability of private life, autonomy, bodily integrity, the right to information and participation – and which codifies and enshrines the basic principles, values and objectives of mental health policy;

20. Calls for the adoption of common European guidelines defining disability in accordance with the provisions of the UN Convention on the Rights of Persons with Disabilities;

...

Combating stigma and social exclusion

44. Calls for the organisation of public information and awareness campaigns through the media, the Internet, schools and workplaces, in order to promote mental health, increase knowledge about the most common symptoms of depression and suicidal tendencies, destigmatise mental disorders, encourage people to seek the best and most effective assistance and promote the active integration of people experiencing mental health problems;
45. Stresses the crucial role of the media in changing perceptions of mental illness and calls for the development of European guidelines for responsible coverage of mental health by the media;
46. Calls on the Member States to support and encourage the empowerment of organisations which represent people with mental health problems and their carers in order to facilitate their participation in the formulation and implementation of policy and in all stages of research into mental health;
47. Considers that de-stigmatising mental illness involves abandoning the use of invasive and inhumane practices as well as those practices based on the custodial approach;
48. Considers that it is necessary to promote and support psychological and social rehabilitation activities delivered by small public, private or public-private residential centres which provide day-care facilities or continuous care, are similar in scale and ethos to family units and are located in an urban setting, so as to encourage residents' integration at every stage of the therapeutic and rehabilitation process;
49. Welcomes the Commission proposal for a new directive against discrimination on the basis of religion or beliefs, disability, age or sexual orientation beyond the employment sector and calls for the immediate adoption of this directive in order effectively to protect persons with mental health problems from discrimination;
50. Calls on all Member States to ratify without delay the Hague Convention of 13 January 2000 on the International Protection of Adults;
51. Instructs its President to forward this resolution to the Council, the Commission, the governments and parliaments of the Member States and the European Office of the WHO.

