

Promoting Social Inclusion and Combating Stigma for Better Mental Health and Well-being

Thematic Conference Combating Stigma and Promoting Social Inclusion organised by the European Commission and Ministry of Health of Portugal, in cooperation with the European Commission's Directorate General for Employment, Social Affairs and Equal Opportunities and the Ministry of Labour and Social Solidarity of Portugal, and with the support of the Belgian Presidency of the Council of the European Union.

CONCLUSIONS FROM THE CONFERENCE

- Although mental disorders are common, they are associated with stigmatisation (including self-stigmatisation), prejudice, and the experience of discrimination, social exclusion or self-withdrawal from society. Such experiences are extremely counterproductive, causing untold suffering, making recovery more difficult, decreasing help-seeking, delaying care and treatment and affecting not just the individual, but their families and even the professionals who working in mental health services.
- Stigma and discrimination reach all areas of life, from the private to the public and work-related domains. Stigma and discrimination on the basis of mental health problems must become as unacceptable as other forms of discrimination, such as racism or homophobia. Social, economic and demographic factors risk increasing stigma, so it is critically important that immediate action is taken to reduce stigma.
- The goal of making society tolerant to people with mental illness should be replaced by the goal of their inclusion in society despite the fact that they might be different. Or, as one speaker put it “the idea should not be to mainstream people with mental health problems, but to broaden the mainstream, so that it can include those with mental health problems”.
- The primary goal of anti-stigma work is not a change of attitudes but a change of behaviour. The reduction of discrimination (behaviour) is more important than the elimination of the stigma (attitude) that produces it, as discrimination can be measured in meaningful terms and monitored and is also more susceptible to change, which can be achieved faster.
- The most effective approaches are long-term, adaptable to local circumstances, with consistent general principles and messages and which focus on tackling discrimination by changing behaviour, in particular through (i) the inclusion of social services in mental health services, (ii) the promotion of direct contacts, on an equal basis, between the public or targeted professionals and people with mental health problems, and (iii) their empowerment and the protection of their rights.

More specifically, this includes:

Empowering, involving and consulting service users, experts by experience and informal carers

People with direct experience of mental health problems have valuable expertise to offer, in addition to the knowledge of professionals without direct personal experience.

- People with direct experience of mental health problems should be involved in the planning, design, delivery, monitoring and evaluation of mental health policies and services.
- Goodwill towards organisations of service users needs to be backed up with meaningful involvement at all levels, and financial support to ensure that organisations have the means to employ democratic and transparent methods.
- Informal carers, who carry a large part of the burden of care for people with mental health problems, should be involved in the design, delivery, monitoring and evaluation of mental health policies and

services. It is important to note that their inclusion is separate to that of service users and experts by experience themselves.

Putting in place high-quality, community-based and comprehensive mental health services and moving away from large institutional models, where possible

The quality and accessibility of mental health services and the way in which they are organised and delivered are important determinants of the level of stigma in mental health. Treatment in large, impersonal, isolating institutions and low-quality mental health services support the (self-)stigmatisation and discrimination against people with mental health problems and their social exclusion.

- There is a need to move to community-based, decentralised, transparent mental health services offering accessible and affordable high-quality treatment and care.
- Implement quality assessment and assurance systems for services, using internationally recognised tools, such as the ITHACA, DEMOBinc and QuIRC toolkits.
- Involve users of services in design, delivery and evaluation of service outcomes, using the Empowerment Indicators.
- Medical interventions and treatment plans need to be recovery-oriented and complemented by social support measures (including placement and support in jobs, education or other meaningful activities).

Placing mental health in the context of social and local development

Promoting mental well-being in the population and supporting the recovery of those with mental health problems must be seen and addressed as a well-being issue in the broader context of social and local development, rather than a purely clinical issue.

- Mental health councils or mental health coordination committees at local level, sometimes working under the coordinating responsibility of mayors, which regularly bring together all relevant stakeholders and promote their coordination and partnership have proven to be effective.

Enabling people with mental disorders to exercise their rights

People with mental disorders have the same human rights as others. These human rights must be safeguarded and people with mental health problems should be enabled to exercise their rights as citizens.

- Given its importance for recovery, those with mental health problems should have access to financial support, equivalent to those with other health problems, to protect their independent living, access to housing and employment.
- The EU and all Member States should sign and implement the United Nations Convention on the Rights of Disabled People (CRPD). Mental health law, including the need for restriction or compulsion should be reviewed regularly with public involvement to ensure that core principles of human rights are maintained. Legislative gaps, where mental health law differs from civil code should be addressed.
- People with mental health problems should not be prevented in law from voting not standing for office in any EU country.

Strengthening social protection to prevent mental health problems

Primary and secondary prevention of mental disorders in specific and general populations can be achieved through a number of different public policy sectors.

- Addressing risk factors relating to the recession and to social determinants of mental health can improve population mental health. Evaluation of social inclusion and anti-poverty measures should include mental health and well-being outcomes.
- The mental health needs of specific populations at risk of social exclusion, such as prisoners, young people, and those in institutions, should be assessed and addressed.

The role of the EU

EU-health and social policies play important roles in promoting the exchange of experiences between Member States, in coordinating their policies and in encouraging leadership and reform.

EU-Structural funds are the major EU-level financial instrument to support Member States and regions in their actions. Member States and regions are themselves deciding how to use structural funds.

Member States and regions should be encouraged to use structural funds to support the social inclusion of people with mental health problems and to improve the quality of mental health systems.

Mechanisms are needed to ensure that structural funds are not used to prolong the use of out-dated institutional infrastructures and care models rather than for their replacement by community-based and socially included care, as intended.

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CONFERENCE MINUTES

MONDAY 8TH NOVEMBER 2010

1200-1245 | OPENING PLENARY SESSION

Commissioner John DALLI, European Commissioner for Health and Consumer Policy, welcomed participants to this fourth conference in a series of five working to implement the European Pact for Mental Health and Well-being.

Commissioner Dalli introduced his remarks by reiterating that Europe is about improving the lives of European citizens. Because of this, he emphasized the emphasis within the EU strategy for growth on addressing the challenge of promoting a healthy and active population and reducing health inequalities and social exclusion. The Commissioner introduced some top line facts about the burden of mental ill health, including the statistic from the recent Eurobarometer survey that one in seven Europeans had sought help for a psychological problem in the last year. He pointed to the high direct and indirect costs of mental ill health to societies as a reason for the development of synergies between health and social sectors to improve care and treatment for those with mental ill health. There was also concern at the rate of mental ill health in young people, and the potential for this to effect the participation of these young people in the workforce of the future. Taken together, these facts point to the need to address mental health issues, both for health and solidarity reasons, as well as for economic reasons.

Commissioner Dalli went on to introduce the European Commission's thinking on mental health going forward:

- Firstly, the Commissioner pointed to the need to support people with existing mental health problems. He emphasized the need for health services to adapt themselves to ensure that high quality care and treatment is available to those who need it. The Commissioner noted the fact that several Member States were advanced in this regard, and pointed to the work Member States such as Portugal had done to develop and support community based support infrastructure and services.
- Secondly, the Commissioner discussed the need for greater social support for people with mental health problems to take part as active citizens. Employment for people with mental health problems is a key part of that, and measures to support people into work should be balanced by activities to improve understanding by employers. There is a place for anti-stigma and awareness activities in different settings. The Commissioner pointed to the success of the joint Commission and WHO Project on Empowerment of people with mental health problems.
- Thirdly the Commissioner emphasized the need to promote mental health and help prevent mental disorders amongst populations that are most at risk. He pointed to activities to address dementia in later life, whilst reminding the audience not to forget the needs of the wider population. The commissioner

pointed to initiatives such as French local mental health councils which ensured that a balance of physical and mental health needs were included in measures to promote economic objectives on a local and regional level. The decision by the European Committee on the Regions to include mental health as a priority was warmly welcomed.

In closing the Commissioner pointed out the potential for activity on other policy objectives to assist in improving mental health. In particular he pointed to the long term potential for mental health of national targets to reduce poverty by 20 million people by 2020

Ana JORGE, Minister of Health, Portugal, welcomed the participants to Portugal for the conference. She was delighted to take part and delighted that she was sharing a platform both with Commissioner Dalli and with her Ministerial Colleague Mme André.

Mme Jorge emphasized the importance of the European pact for Mental Health and Well-being, and was pleased to reaffirm the commitment of the Portuguese government to the Pact and its implementation. Portugal is particularly pleased to see the inclusion of stigma and discrimination within the Pact. Mme Jorge went on to introduce several areas of progress in Portugal in which action at an EU level had assisted in the definition of policy.

Portuguese legislation now includes explicitly the need to include service users in the development of mental health services, and the development of policy. Mental health services are developing according to the national plan for mental health. This includes substantial developments in community based services, and new approaches to the training of professional in the field.

The Portuguese government is informed by evidence in its approach to developing policy. In recent years it had been concerned with the prescription of psychoactive medication, and has just launched new measures within this framework. Effective anti-psychotic medication will now be available free of charge to people who require it. This is a step forward to widening access to appropriate treatment. There will be an elaboration of evidence based guidelines for the prescription of psychiatric medicines to guide professionals in prescribing appropriately. Twinned with these measures there will be a development and training programme in primary care, to enable general practitioners to prescribe and support people on medication. Mme Jorge feels that these measures will improve the patient experience, and address the problem of over prescription, something which has been a factor in Portugal as in other Member States.

Maria Helena ANDRÉ, Minister of Labour and Social Solidarity, Portugal, welcomed the remarks of Commissioner Dalli, and Mme Jorge, and was very pleased to be able to participate in an important conference on mental health alongside her colleague from health.

Mme André was happy to share some of Portugal's progress in the field of social inclusion and anti-discrimination, describing this as a vast field in which the country had made great strides forward. The key to this has been to move the paradigm forward to communities respecting differences and including people no matter what their individual differences. Portuguese legislation sanctions prohibition of direct or indirect discrimination on any grounds. This law is one of the first at EU level and marks a practical translation of political rights to implementation. People with mental health problems cannot be an exception to discrimination laws and are included in Portuguese measures.

There are several fundamental pillars of employment and social inclusion policies, which are particularly important for people with mental disorders. There has been a deep transformation in structures to support families. There has been a focus on vocational activity and involvement of individuals in society.

Portugal has now created a new collection of specific support measures for people with psychosocial incapacity. There has been a reorganization of existing responses...for example by making services age appropriate at all stages of the life course. Proximity to the community is very important, with different responses according to level of incapacity.

A key stakeholder and partner is the NGO or 'third' sector. They work alongside health and social care, taking care of civil and community participation needs to ensure true involvement in communities in which people with mental disorders live.

Nace KOVAC, President, Mental Health Europe, started by stating that he was proud to represent Mental Health Europe (MHE) on behalf of its member organisations across Europe. He welcomed the cross-policy working advocated by the Portuguese Ministers, and the remarks of the Commissioner with regard to addressing mental health in a collaborative way. These approaches are a good fit with the work of MHE, whose members rely on the coordination of policies and services in different sectors.

Mr. Kovac pointed out that there is often an inequity in the distribution of funding between disability services and mental health services. MHE believes in and campaigns for mental health to be recognised as a component of all measures to support disabled people, and to ensure equality and rights for them.

Mr. Kovac highlighted the role of NGOs and civil society organisations in participatory democracy, particularly in times of change and economic hardship. NGOs can use their experience at the grass root to engage with humanitarian issues, and the reality of poverty, discrimination and inequality, bringing this to policy environments.

MHE strongly advocate for the involvement of people with first hand lived experience of mental ill health in the design, delivery and evaluation of mental health services and anti-stigma activities. Self-help and self-management have been shown to be empowering. Empowerment strategies should be key at every level.

CHAIR:

The session chair, **Nessa CHILDERS**: Member of the European Parliament, Ireland East Mrs. Childers has a long interest in mental health, having worked as a psychotherapist before entering the European Parliament. She made some personal reflections on the experiences of stigma she had been recounted through her practice, and the knock on effects of this experience.

Mrs. Childers recalled that the validation of having something heard, and received was a great boost to people with mental health problems. Often people don't like themselves and may even hate themselves, so it is very difficult for people to feel good about things. She recounted the story of person with depression who on waking felt the dread of the day, not being able to get up but having to get up and be normal in work, despite feeling alone. That person wants someone to know but can't say anything, because stigma is the thing that stops them. In the face of stigma they show huge courage to get through the day and face the next.

Mrs. Childers contrasted this story with how different things might be if that person could reach out to colleagues, friends and family as well as services. She asked participants to bear in mind what might need to change to enable that to happen.

SPEAKERS:

In introducing his topic, "Reducing stigma and discrimination of people with mental health problems", Professor **Norman SARTORIUS**, President of the Association for the Improvement of Mental Health Programmes, asked participants to bear in mind one core principle when considering stigma in relation to mental illness, namely that any society that will discriminate for any reason is a society that will not survive.

Stigma now and in the future

Many diseases are subject to stigma, defined as a negative attitude towards a difference which results in discrimination and leads to social exclusion. Devastating illnesses such as Leprosy and STDs such as AIDS are subject to stigma. Professor Sartorius argued that the stigma in relation to mental illness is particularly corrosive as it is persistent over many years, trans-generational in its effect on the family of people affected, and even affects professionals who work in the care and treatment of people with mental illness. Almost uniquely the stigma of mental illness transcends the individual. One of the most damaging aspects of stigma is that it undermines a person's already fragile self image, therefore causing those people to reject or not access many of the treatments they might be helped by.

Mental health activities have been underway for years, on policy and practical levels. Stigma is the critical common denominator in most mental health work and the greatest barrier to improvement of mental health and mental health services. In the last few years we are starting to see success in anti stigma activities. There are tools to help us fight stigma that should be utilised. Though progress is being made, Professor Sartorius outlined several reasons that he believes will be responsible for an increase in stigma in the years ahead.

There is a global reduction in social capital on an individual, family and community level. The interpersonal relationships people have are changing as are family structures and sizes. This can reduce the availability of people to support and nurture people with mental ill health. Citing the disappearance of classical communities, Professor Sartorius expressed concern both that risk factors for poor mental health are greater where there is less of a sense of community. He also expressed concern that health systems are geared towards traditional geographical communities, when people are now engaging in non-traditional ways. Finally, he drew attention to the ever increasing complexity of life, in employment, relationships and things like technology. These circumstances may make any impairment in function more noticeable.

A New Strategy for Fighting Stigma

Professor Sartorius outlined some of the components that he felt could form the basis of a new strategy for combating stigma:

- Planning, development, execution and evaluation of activities to reduce stigma must involve people with mental illness, and carers at every stage.
- The primary target of anti-stigma work is not a change of attitudes but a change of behaviour. This is a major shift in emphasis.
- The reduction of discrimination is more important than the elimination of stigma that produced it. It is important also that it can be measured in meaningful terms and achieved faster.
- Short lasting campaigns against stigma are not particularly useful: long term programmes incorporated into other efforts are needed to make a difference.
- Making society tolerant to people with mental illness is an obsolete goal which should be replaced by their inclusion in society despite the fact that they might be different
- Fighting stigma and discrimination with success is possible regardless of the size of the national income or of the co-existent problems in that nation.
- Programmes against stigma should adopt general principles but their activities should be tailored to fit local circumstances

Europe has substantial assets for anti-stigma activities

Europe has a wide range of assets which can be brought to bear in fighting stigma. There is good evidence from a range of regional, national and international programmes which show positive results and the benefits of collaborative cross sector working. The effect of stigma and of mental illness is increasing across Europe, and the drive to combat stigma and discrimination fits well with European activities on human rights. Finally the importance of mental health and wellbeing to success at a population level is becoming clearer to decision makers. This in turn makes it more likely that good initial research can be built upon with more support.

Conclusion

Professor Sartorius identified stigma and discrimination as the single largest barrier to improvement in mental health and mental health services. Reducing stigma and discrimination will assist people who live with the effects of mental illness to be part of the society in which they live. It will also change that society for the better.

Professor **José-Miguel CALDAS DE ALMEIDA**: National Coordinator for Mental Health, Portugal, started his presentation with an overview of the burden of mental ill health in Europe and a sense of the prevalence of stigma. Across Europe the prevalence of any mental disorder in the population is of the order of 10-20% per year. Of these around a quarter of this incidence represents serious mental illness.

Neuropsychiatric disorders are responsible for 19% of the burden of disease. Neuropsychiatric disorders are the first cause of YLD (39.7%) of those attributable to all causes. Unipolar depression, dementias, schizophrenia and bipolar disorders are responsible respectively for 12.4%, 3.9%, 2.3% and 2.3% of YLD.

15% of people with mental disorders had perceived stigma (Alonso J et al 2009) This may be one reason why the use of mental health services is low. Among those with a 12 –month mood disorder, only between 35.8% and 56.0% reported having consulted a general medical professional due to problems with emotions or mental health. Around 3% of EU adult population have unmet needs for mental healthcare, that is to say they experience a mental health problem that has a substantial affect on their life for which they receive no treatment or support. In some cases as many as 50-60% of people with serious mental disorders aren't getting treatment.

Improvement of Mental Health Services

Professor Caldas de Almeida described a number of 'gaps' in mental health care and treatment which should be addressed in order to improve services and human rights:

The Access Gap

- Where people cannot access care and treatment because it isn't available, affordable, or accessible

The Quality Gap

- Where available services are either of poor quality, or are inappropriate,

The Prevention Gap

- Where opportunities are missed for primary and secondary prevention of mental disorders in specific and general populations

The Human Rights Gap

- Where despite progress in many places in Europe people are suffering abuses of human rights, both explicit and implicit.

Professor Caldas De Almeida pointed out some of the barriers to addressing these gaps for service design. He pointed to the success of Portuguese actions to improve mental health services being attributable to sustained political support and funding with ministerial interest and access. In order to keep political interest there is a need to continue producing and disseminating evidence to support policy and service development. Allied to this is a need to ensure that leaders in mental health, including clinicians, are familiar with the public health perspective of mental health. There is a role for a powerful user and carer lobby on these issues, and a risk that if the user lobby loses power then change can be delayed.

Service improvement is not an easy task. There is a need to recognise and manage the temptation to centralise mental health services in institutions and in physical beds when these are relatively easy to monitor in comparison to community indicators. Community mental health services must receive adequate investment, and time to demonstrate outcomes. Successful community services need to work closely with primary care. With many competing issues it is not always easy to reach primary care and effect change.

Professor Caldas de Almeida proposed several actions to improve services:

- Move towards comprehensive community-based services
- Define priorities and strategies: develop a mental health plan
- Assign responsibilities for the coordination of policy and plans
- Ensure participation of users and carers
- Increase research and evaluation
- Use human rights as a service improvement tool

Improving Human Rights in Mental Health

An overview of the key UN and European human rights instruments were given, both in relation to detention and restriction, and in those that relate to the right to the highest attainable standard of mental and physical health. These included the UN Convention on the Rights of Disabled People (CRPD), the International Covenant on Economic Social and Cultural Rights (ICESCR) and the UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (MI Principles)

The key rights in relation to people with mental disabilities within international human rights frameworks relate to:

- Right to the highest attainable standard of mental and physical health
 - Access to appropriate and professional services
 - Right to individualised treatment (MI Principles, CRPD)

- Right to rehabilitation and treatment that enhances autonomy (CRPD, ICESCR, MI Principles)
- Right to community-based services (Art 19 CRPD)
- Right to the least restrictive services (MI Principles)
- Protection of human dignity (CRPD, ICESCR, MI Principles)
- Legal capacity and Informed Consent
- Right to liberty and security of person
- Freedom from discrimination
- Freedom from inhuman and degrading treatment

There are a number of barriers to the implementation of these human rights in relation to mental health. Firstly and importantly there is a lack of awareness of these instruments both in the public mind and in mental health services. Where services are of poor quality or where there are barriers to access the right to treatment is paramount. A lack of legislative frameworks for implementation at a national or regional level can impede the practical implementation of these frameworks. Professor Caldas de Almeida pointed out that one of the barriers to addressing stigma was the fact that when society allows and supports the exclusion of people with mental health problems it reinforces difference. He suggested that there is a complex and indivisible relationship between stigma, service improvement and human rights. It was suggested that we must look to international and regional human rights issues to work on the troika of rights, service improvement and stigma together. Finally and importantly a weakened, unrecognised or reduced user and carer lobby reduced the pressure on political decision makers to ensure change.

Professor Caldas de Almeida proposed several actions to improve human rights:

- Raise awareness of human rights instruments
- Create human rights monitoring mechanisms
- Train stakeholders in human rights
- Develop policies to promote access to good quality care
- Develop laws that protect human rights
- Improve mental health services

CHAIR:

Dr. **Jan WALBURG**, President / CEO of Trimbos-instituut, Netherlands Institute of Mental Health and Addiction, as chair of the session, introduced the panel, explaining that Dolores Gauci had been unable to attend, and would be replaced by Paul Arteel.

OPENING STATEMENT:

Paul ARTEEL, Executive Director of GAMIAN Europe, presented findings from a new survey on stigma in mental health. He explained that GAMIAN is a pan-European organisation with members which are patient organisations in mental health. For several years GAMIAN has been interested in whether stigma and discrimination really is getting better, and opinions are split within member organisations.

In 2006 GAMIAN collaborated with researchers at the Institute of Psychiatry to run a pan-European stigma study to gain an understanding of the experience of stigma in 20 countries. Member organisations cascaded questionnaires and there were 4500 respondents. The survey is currently being re-run, and the objective is to compare results with the baseline of the 2006 survey. GAMIAN then intends to repeat the survey every four years. The survey instrument is validated, and included measures of perceived stigma, anticipated discrimination and empowerment, along with some demographic information. The Questionnaire is available in 20 languages, and in online and offline versions.

Mr. Arteel shared some very preliminary results based on the first 500 responses to the 2010 survey.

- The survey was mainly completed by adults aged 31-59.
- There has been an increase in people living independently compare to 2006 [68%('10) vs 56% ('06)], with fewer people reporting living in residential care.
- Fewer respondents report receiving a salary [24% ('06) vs. 17% ('10)]
- There is an increase in knowledge of diagnosis, and a larger proportion of respondents, and more agree with their diagnosis.
- There is a 24% increase in the number of respondents agreeing that people with MHPs make an important contribution and a similar increase in the number of respondents believing that they can live a good life.
- On the downside, 8% more respondents believe that they shouldn't get married and 4% more think entering hospital in major failure.

Mr. Arteel stressed that these results were based on a small sample, and that it wasn't possible to infer trends from these data. He looked forward to the full data set in 2011.

PANEL PARTICIPANTS:

Mr. **Gyula HEGYI**, Member of the Cabinet of Mr László Andor, European Commissioner for Employment, Social Affairs and Equal Opportunities conveyed the good wishes of Commissioner Andor, who was unable to attend the event, and confirmed the interest and involvement of DG Employment in this event and the Pact process.

Mr Hegyi re-iterated the moral obligation to help people in disadvantage, as well as the medium and longer term economic benefits of including people. He cited recent DG-Employment research with Roma children, which demonstrated the value of including a marginalised group in education opportunities in developing the competencies of those children to now contribute economically as well skilled adults.

Good policy on social inclusion very important to the EU, with inclusion central to three of the five Europe 2020 objectives. One of the most important objectives for future prosperity is the target for 75% employment.

Comparable indicators of progress in this field are important, and relative income, the number of jobless households, and material deprivation are key indicators and targets. There does need to be an understanding of the local context of these though.

The European Platform Against Poverty and Social Exclusion is a new vehicle for action currently in development. It will include a renewed Open Method of Coordination along with a monitoring framework and a method of exchanging good practice on implementation tools. Mr Hegyi drew special attention to reform of the social protection systems, and need to monitor this in Member States. He also pointed to the special situation of those furthest from the labour market, and said that Member States would be required to report on this. Commissioner Andor is very interested in the potential for the social economy to assist people who are furthest from the labour market to gain business skills and benefit communities. This kind of action should take place alongside encouraging large business to include Corporate Social Responsibility in their activities. Finally, the Platform will seek to maximise the use of EU funding for social inclusion. 10% of the EU budget goes to the Social Fund, but there is often a reduced utilisation of these funds for the most disadvantaged. Novel methods of support will be considered, for example micro financing can be a very useful technique for improving access to employment opportunities for people with MHPs.

Michael HÜBEL, Head of Unit "Health Determinants", DIRECTORATE General FOR HEALTH and Consumers, European Commission, expressed his agreement with the words of Professor Sartorius with regard to the place of mental health and illness in our societies. He pointed out that there was a risk in addressing stigma and discrimination in mental health because it cuts across to many areas of policy, requiring collective action. He urged participants to look to consider practical implementation of principles whilst taking part in the conference. Mr. Hübel strongly supported moves to include anti-discrimination in mental health within legislative work. He also pointed to the wider agenda with social fabric in Europe including the shift in the nature of communities. He felt that Europe 2020 presented an opportunity to reconnect with some of these issues following the crisis. Mr. Hübel reiterated the importance of working realistically with NGOs and stakeholder organisations.

Finally, Mr. Hübel explained some of the anticipated next steps for mental health at EU level. Firstly the Pact conferences would conclude in Berlin in March, with the mobilisation of good practice via the Compass Database. The second step would be to translate the activities under the Pact into policy at EU level, on which work is underway with the Hungarian Presidency. Finally, there is the need to mainstream mental health in activities such as Europe 2020 and the empowerment of young people.

Robert ANDERSON: European Foundation for the Improvement of Living and Working Conditions, was interested in the work GAMIAN had undertaken, and had some points to share in relation to the survey work the European Foundation for the Improvement of Living and Working Conditions. Research is extremely important, and survey tools are very useful. Mr. Anderson called for to be care to be taken in developing and designing good questions that enable us to monitor subjective mental health, in order that these issues can be strongly represented in discussions about the future of GDP and measures of national success.

Anderson drew on recent Dublin Foundation reports which showed that whilst people's perception of their inclusion is related to their reported mental wellbeing it is income/deprivation that really matters both to poor health but also in descriptions of good health.

Family support was another important issue, and Anderson was pleased to see that the needs of carers had been specifically included in the conference. Employment is seen as the ultimate method of improving social inclusion. Although we know close to 90% of people with mental health problems want to work there is a degree of ambivalence and for many people family roles are important. There is a need to look at employment and mental health across the life course, from ensuring that young people with poor wellbeing or mental illness do not become benefit dependent, to ensuring that older people transition to retirement in the most mental health promoting way. Finally, it is very important to consider the wellbeing of those delivering health and social services, and the pressures they face in time of cuts.

When asked for a key research objective by Dr. Walburg, Mr. Anderson pointed to later life and demographic ageing.

John HALLORAN: President, European Social Network (ESN), introduced ESN as a network of local/regional service managers at a local level. Services can vary from health, to social care, education, and increasingly in multidisciplinary service. ESN members manage service by delivering or by contracting them out, and are key for putting into practice local services.

Mr. Halloran sought to place the local and regional in the context of the national and transnational. The words regional and local both evoke a sense of place. The places in which work and live their lives are key to mental health. Communities can be both positive and negative determinants of health, and regional and local authorities have a key role in this. They are critical in fighting discrimination, and creating opportunities to have dialogue, articulated by clear political leadership. Local public planning with economic development is interconnected and interdependent with services.

Mr. Halloran called on local authorities to be more effective at demonstrating the social return of their activities. He pointed to the importance of local service quality. Services must be person centred, responding to needs and not fitting people to things that are available. There is a need for multi-level cooperation to enable local, effective, tailored services. Where health and social care are responsibilities of different levels of government there is a risk of things falling through gaps.

Community based services can themselves exhibit institutional attributes, and community services themselves can incubate stigma. That said local authorities are huge employers and there are opportunities for them to support and be involved with anti- stigma activities and demonstrating good practices.

Mr. Halloran was concerned that the economic predicament might force authorities to place economic growth in front of all other activities, but advised councils to include mental health and wellbeing in these activities through involvement of stakeholders in community planning and services across the spectrum.

Dr. **Dinesh BHUGRA**, President of the Royal College of Psychiatrists, UK, expressed his delight in taking part, and the commitment of the Royal College of Psychiatrists to the Pact and to working with partners across Europe. He suggested three challenges to bear in mind:

- **Public mental health.** We need to encourage people take control of their mental health, getting early intervention if needs be and receiving support. This is not just a health issue but an issue for education, criminal justice and numerous other policy fields outside health. Stigma can play a role in preventing the issue being taken up.
- **Potential impact of economic downturn on mental health services.** The numbers of people with mental health problems will rise as economic factors affect the population. At the same time there will be a need to make savings in public spending. There is a challenge in supporting people and ensuring that they can access services that are geographically and emotionally appropriate.
- **The quality of services we provide.** Service quality is not as much about what kind of room or facility in which care is delivered but quality of the process; what that contact is, what the quality is and what end it achieves. Where there is internalised stigma against psychiatry there is a challenge to recruit the best people with the skills to achieve those outcomes into mental health services.

Dr. Bhugra was asked for an opinion on the discussions around the over-medicalisation of distress. His own view is that psychiatrists are doctors, and that the role of the medical practitioner is much broader than just the organic. He believes that doctors need to know and care about the spiritual, psychological and social aspects of their patients' lives.

Professor **Tamas KURIMAY**: Representative of the Ministry of National Resources of Hungary, President of the Hungarian Psychiatric Association, outlined the mental health components of the forthcoming Hungarian Presidency, which will include patient and professional pathways in Europe as its key health theme. The Presidency will hold an event to consider the role of health-promoting behaviours on health as a whole. The Presidency is committed to drawing conclusions from the series of Pact conferences, drawing together the conclusions from the conferences following the final even in Berlin in March under the Hungarian Presidency.

Dr. **Matt MUIJEN**: Regional Advisor for Mental Health, WHO Regional Office for Europe, stated that discrimination and social inclusion in health and mental health was core to WHO, and this work is critical. He spoke of several pieces o WHO Europe work. Mental health is going to be central to the emerging social determinants of health discussions in WHO Europe. The indicators of Empowerment developed by the recent WHO/EU partnership project are very useful, and it is hope that these can be taken forward. Professor Kristian Wahlbeck has just completed a paper for WHO on the consequences and actions of dealing with the crisis which as recently been published. Who is now starting to look at the mental health dimension of migration in Europe.

Dr. Muijen reminded participants that whilst adopting and promoting the public health aspect of mental health we must also continue to protect the most vulnerable. We must ensure that that rights are protected, and opportunities to make savings do not become opportunities to remove entitlements and services from those that need them. Service demands are going up whilst capacity to deliver are falling. This is going to be difficult, especially if cuts are focused on services for people with severe mental illness so as to jeopardise services to assist people with mild to moderate mental health problems to maintain or regain work. Dr. Muijen reminded participants that we are entering a time when effectiveness and efficiency will be very carefully scrutinised. He said that efficiency was about more than money, in that those with highest need may need greatest level of investment.

DISCUSSION

There was a lively and engaging discussion from the floor. **John McCarthy** (Mad Pride Ireland) asked that participants be aware that not everybody subscribed to the medical model of mental health, drawing on his personal experience of recovery through connecting to human values whilst rejecting medical labels. He pointed out that not subscribing to a medical model can lead to threats of restriction or the invalidation of input to debate. He was unhappy that there was no voice of lived experience on the panel. In a point echoed by **Ann-Laure Donskoy** (ENUSP) he called for the need for service user and carer voices to be heard separately, and not included as one voice when there are important differences in perspective. Ms. Donskoy emphasised the competence and willingness of service user researchers to be part of efforts to improve the quality and diversity of evidence in this field.

Lise Jul Pedersen (Denmark) spoke from a user perspective of the need to balance physical and mental health. She had found it hard to have physical health needs met in other healthcare settings, and suggested that a more holistic view of health could increase the physical health of people experiencing mental health problems as well as the mental health of those with physical illness.

Arne Holt (Norway) drew attention to the use of language in mental health, in particular the distinction between so called 'severe' mental illness and more 'mild' conditions. We associate 'severe' with psychosis, bipolar or anorexia. We often associate 'mild or moderate' with depression and anxiety, when depression is the most frequent and can be the most disabling. Artificial distinctions are unhelpful. For example, death rates by suicide are similar across these groups. Outcomes also vary, with a person with well-managed psychosis in employment, and a person with poorly-managed anxiety not.

CHAIR:

Lynne FRIEDLI, independent expert researcher on mental health, chaired the first parallel session, on social protection, social inclusion and mental health. She introduced the most relevant aspects of the issue, such as the role of social determinants on population mental well-being and the impact of social protection measures in times of economic crisis, and explained that these should be addressed in the session.

SETTING THE SCENE:

Lorenzo RAMPAZZO, from the European Social Network and Director of the Veneto Region Mental Health Office, introduced the session by proposing a model of institutional, professional and economic integration in three areas: Social and health services; Hospital and Community-based services; and, Public and Private Services. The Mental Health Department was proposed as the institution in charge of the overall coordination and planning in each area, in cooperation with NGOs and associations of users. This model should allow for a personalized treatment programme, along with a wide range of community-based services. Advice on involving all relevant stakeholders and overcoming the fear and stigma which can surround these issues was also provided.

PRESENTATIONS:

Jean-Luc ROELANDT, Director of the WHO Collaborating Centre in Lille and **Marianne AUFFRET**, representative of the Association "Elus, santé publique et territoires", introduced the Local Mental Health Council (MHLCC), a powerful tool, brought about by the local electorate, for local coordination of relevant partners, including mayors, service users, families, social and health services. Additional roles of the Council include promoting partnership with and facilitating access to relevant resources such as leisure, education or housing, or providing training in specific areas. The project is a National Programme in France, with a concrete legal framework. 37 MHLCCs have been developed so far, involving either a concrete district in large cities or several municipalities. These are coordinated by the WHO Collaborating Centre in Lille.

Simone GIOTTO, from the secretariat of the EUREGHA network, Veneto region in Italy, introduced the EUREGHA Working Group on Mental Health. The EUREGHA network was described as a Brussels-based network composed of 108 regional and local representatives across 18 Member States, which are active in public health. The network was born in 2006 and aims to create synergies and coordination among regions, as well as to increase the voice of local actors in European policy making. A number of actions have been developed already. One of these is the creation in 2009 of a *Working Group on Mental Health and Suicide Prevention*, which brings together regional stakeholders with concrete initiatives on mental health, and aims to exchange best practices on depression and suicidal behaviour, and to identify priority activities. A large-scale project on suicide prevention was presented as a relevant outcome of the group, involving 11 of the EUREGHA network partners. This project is intended to assess existing tools and local needs, to provide guidelines at local level and to promote the creation of local networks among health care providers.

Paula DOMINGOS, from the National Mental Health Coordinating Body at the Ministry of Health, Portugal, presented the Portuguese Project for the treatment of Homeless People, which represents a coordinated effort to accomplish concrete objectives of both the National Mental Health Plan 2007-2015 (developed by the Ministry of Health) and the National Strategy for Integration of Homeless People 2009-2015 (developed by the Ministry of Labour and Social Solidarity). The pilot programme, which is being developed at the regional and local level, aims to ensure the access to psychiatric/psychological services to homeless people with severe mental

disorders and no medical follow up. A number of case managers have been designed which are responsible for the referral of those in need. These include professionals from both health (public and private), and social sector. The project includes a Partnership Protocol between the National Mental Health Coordination body and the Psychiatry Hospital Centre in Lisbon, which has the necessary know-how and the experience. Medication costs are covered by the National Health Care System.

DISCUSSION

During the discussion, the participants identified the following **priorities** for action:

1. Empowerment of users and carers
2. Indicator monitoring could and should include social inclusion monitoring.
3. Mobilisation of local stakeholder and informal networks in mental health activities
 - including elected representatives
4. Establishment of local mental health committees/councils with wide and powerful stakeholder representation
5. Labour market integration
 - income equity
6. Developing meaningful and de-stigmatising mental health concepts and terminology
 - E.g. non-professional services, in addition to those run and offered by mental health professionals
7. Prioritise social determinants of mental health and acknowledge the limited role of health services in mediating these determinants
8. Easily accessible mainstreamed services and support in the community
9. Learning from the intellectual disability field – that there is a long distance travelled in between abolishing institutions and adopting de-stigmatising language.

CHAIR:

Mrs. **Catherine GONZI**, Patron of the WHO Regional Office for Europe /European Commission partnership project "Empowerment in Mental Health", was honoured to attend the conference and to chair the session. She has a long held interest in mental health and wellbeing. This started with a direct family connection as a carer for her brother, who has bipolar disorder. Mrs. Gonzi became involved with the carer movement in Malta, and was involved with the establishment of the Richmond Foundation in that country. Catherine Gonzi also served as a member of the National Mental Health Commission, appointed as part of a national reform process within this sector. On the Commission, Mrs Gonzi represented families of persons with mental health problems. As the spouse of the current Prime Minister of Malta Mrs. Gonzi has worked to raise the profile of mental illness within Malta, and in meetings with the spouses of other European leaders.

SETTING THE SCENE:

Professor **Wolfgang GAEBEL**, President, German Action Alliance for Mental Health, sought to give an overview of the state of the art in relation to stigma, and to summarise some activities in the field with suggestions for how these can be taken forward.

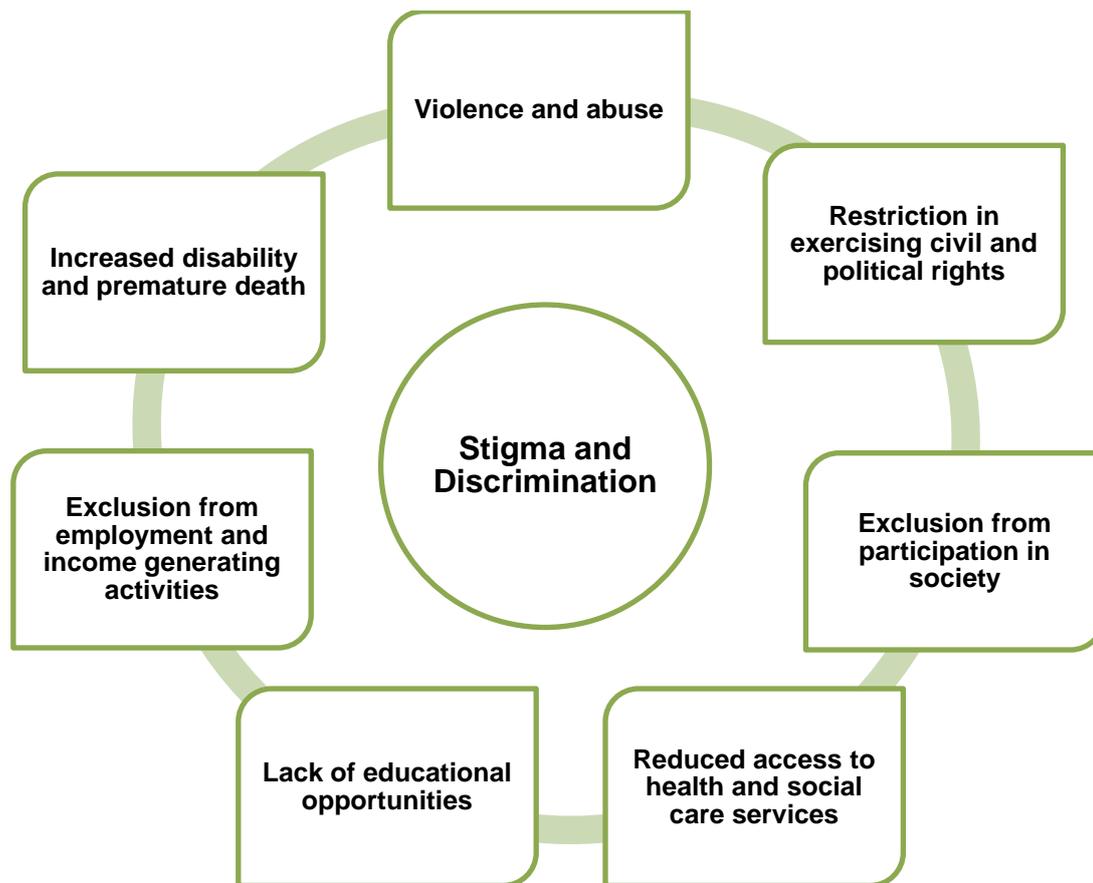
Stigma and discrimination were described as reaching all aspects of life (fig 1 below), including the development of anticipated discrimination (where people expect discrimination and are inhibited from acting) and self-stigma (where individuals believe that they are unworthy because they are told that that is the case) The process of stigma and discrimination is an interconnected vicious cycle which encompasses social exclusion, a lack of access to treatment, economic factors, and the pervasive stigma that affects family members and professionals in the field. Professor Gaebel also pointed to an unintentional policy stigma, where other health and disability issues are given priority over mental health, often because they are seen as higher profile with the public, or because there is a stronger lobby.

Professor Gaebel went on to summarise some of the key activities that can be undertaken to fight stigma by targeting cognitions (knowledge), emotions (attitudes) and discriminatory behaviour (social exclusion).

Professor Gaebel introduced the idea of user empowerment as a strategy against discrimination. The target of empowerment could be to enhance service users autonomy and self-determination, and enable them to develop and pursue their own interests. Strategies for meaningful empowerment include leadership programmes to enable users of services to engage and collaborate in policy and research, and peer support, in which service users are employed in vocational training or in frontline services because of the value of their personal lived experience.

The German Alliance for mental Health is a tripartite partnership between professionals, carers and users with 65 member organisations. They have developed and evaluated activities directed at the public, interventions to target groups (school, student, Police), and workplace activities. The Alliance conducted a survey on evaluated activities, and a systematic literature review with good practice examples (www.seelische-gesundheit.net)

Figure 1 Dues to stigma and discrimination, people with metal health conditions are subject to many fields of discrimination



For success, Professor Gaebel pointed to some key factors for anti-stigma activities:

1. They should combine methods (including contact with people with mental illness, education, and protest against concrete examples of discrimination)
2. They should act at different levels (individual, on target groups such as healthcare workers or schools, and on a societal and policy level.
3. They should emphasise and celebrate user involvement in the development, implementation and evaluation of campaigns.
4. They should be long term, with a range of interventions of different types.

Dr. **Anja BAUMANN**, World health Organization, Regional Office for Europe, introduced the WHO Regional Office for Europe/European Commission Partnership Project "Empowerment in Mental Health", which recently concluded, having developed a set of empowerment indicators. People with mental health problems have lacked a voice for centuries, and they continue to be at severe risk of marginalisation. A key strand of recovery and empowerment is to enable people to take up opportunities to contribute and exist in communities. WHO started the empowerment project to support Member States in increasing the empowerment of people with mental health problems.

The project brought together 23 individuals representing different user and carer associations across Europe. 19 main indicators of empowerment were created, and launched at an event in October 2010. 100 examples of practice from across Europe have been produced as part of the project.

Dr. **David CREPAZ-KEAY** Mental Health Foundation, UK, discussed some of the challenges in developing indicators for empowerment. User involvement has long been included as an extra 'nice to have' and in order to cement the position of user involvement in all areas it is vital that we ensure that it is a properly evidenced and

effective process. The key challenge in the empowerment project was to find a set of indicators that were genuinely useful and relevant across member states, with different cultural and other contexts.

There were many balances to be considered and some compromises to be accepted, but the final indicators sought tried to be fit within a rights based framework; were relative rather than absolute; and were relevant within services and beyond.

Dr. Crepaz-Keay went on to speak more about the project and his own personal views on empowerment. Ultimately Empowerment means different things to different people. Sometimes it is about getting access to service; sometimes access to right services and for some it is about the right to decline services. Empowerment was described as a process, which sometimes required a redistribution of power, and the reaching of compromises to achieve win/win conditions for the widest range of stakeholders. Empowerment needs to impact on individuals, organisations, communities and countries. Achieving empowerment will require more than just financial resource. It will require a change in thought and action, which is far harder to achieve.

Aude CARIA, WHO Collaborating Centre Lille, France, introduced National Mental Health Week (NMHW) in France as a national annual rallying point for media and campaigning action on mental health. The week was started some 22 years ago by the French association of psychiatrists, but has grown steadily and now includes stakeholders from across a range of fields (users and families' NGOs, health and social professionals, local elected NGOs). They work together to raise the profile of mental health and de-mystify mental illness and mental health services for the public.

In the absence of a French national top-down anti-stigma strategy, Mental Health Week in the third week of March provides an important locus for campaigning preparation and action each year. The theme of the annual week and the communication material are provided by a National Coordination Committee gathering representatives of all stakeholders, and run by the WHO Collaborating Centre. Local activity at all levels is invited, using the idea of reducing social distance as the theoretical framework to fight against stigma. Then all stakeholders across country undertake actions, at a local level: debate, conference, informal meeting, exhibition, open doors, movies...).

There is no defined funding, and the coordination work does not benefit from funding by pharmaceutical companies. Ms. Caria emphasised that the goodwill-based engagement was a hallmark of the event. Costs are borne by the participating organisations, including the time spent by volunteers.

A qualitative evaluation is performed annually, including the production of a digest of media activity. The National Coordination Committee logged over 350 local events across France in March 2010. The NMHW acts as a major tool to enhance local partnerships on Mental Health issues and raising awareness of local electorate. A key target for the future is increasing the reach of local events by up-scaling local partnerships, through the development of Local Mental Health Councils, which are platforms of dialogue and coordination for MH issues, on a given territory.

Ms. Caria reflected on the difficulty faced with coordinating dates for campaign activities, pointing to the many campaign days or weeks designated in different Member States, in addition to World Mental Health Day on the 10th October. She suggested that coordination on an EU level might be a useful mechanism for increasing the profile for the week.

Ms. Caria left the audience with the warning that whilst there was a place for awareness campaigns, that this could not be at the cost of the development and support of good quality community mental health services and the improvement of users' rights. The three issues of stigma, service improvement and rights should be addressed jointly.

Ms. **Isabella GOLDIE**, Chair, Scottish Mental Health Arts and Film Festival, introduced the Scottish context for the Mental Health Arts and Film Festival. Scotland is a country of the United Kingdom with a population of 5 million. Since the devolution settlement in 1999 many of Scotland's functions including health, education and

legal systems are governed by a Scottish Government and Scottish Parliament. Other functions, such as macro-economic policy, social protection and equalities are retained by the UK Government. Mental health policy and law is therefore by the Scottish Government, but controls of many of the factors affecting mental health in Scotland are reserved. Mental Health was an early priority of the devolved administration, and the Mental Health (Care and Treatment) Act 2003 was one of the first major bills passed by the Scottish Parliament. The parliamentary process in Scotland enable the wide involvement of all stakeholders in the process, and users and carers were able to give evidence to parliament. The Act is built on a set of principles which include non-discrimination, least restrictive alternative and reciprocity. Local authorities are also required by law to demonstrate that they provide opportunities for people with mental illness to gain employment, education, leisure, housing and other services.

Scotland has had several successive policy initiatives to improve and develop mental health services, with the current plan 'Delivering for Mental Health' launched in 2008. The Scottish Government also sets strategic targets for local health authorities to meet, which include mental health measures such as reduced anti-depressant prescription and reduced re-admission to hospital. The National Programme to Improve the Mental Health and Wellbeing of the Scottish Population ran from 2001-8. This coordinated programme on public mental health included the launch of the 'see me' anti-stigma campaign; the development of Choose Life (the national suicide reduction plan); and the development of the Scottish Recovery Network to promote recovery oriented practice in mental health services. These public mental health actions are now coordinated under a policy initiative called Towards a Mentally Flourishing Scotland. The Scottish Government supports an independent national user organisation, Voices Of experience (VOX), established in 2005.

Mr. **Lee KNIFTON**: Director, Scottish Mental Health Arts and Film Festival, introduced the Scottish Mental Health Arts and Film Festival as a mainstream arts festival that aims to encourage social change in the way the public see and respond to mental health issues, paying particular attention to inequalities. Mixed methods and media are used to influence audiences, media, opinion formers, and 200 partner agencies ranging from Government to The Arts Council.

The festival is approaching its 5th year, and so far it has delivered 600 events to 40,000 audience members across Scotland. Several thousand more people have visited exhibitions or engaged via online, street teams and media coverage. Events cover a wide range of arts genres, and utilise a range of venues from the streets, to iconic Scots buildings and landscapes.

The festival is hosted by the Mental Health Foundation, and coordinated via a national consortium of 200 organisations and 10 national partners. These organisations contribute time, resource, access, premises and expertise to the work, but do not benefit financially from the festival. Through this model the festival has fostered links with venues, artists, and professional services organisations which have enabled it to utilise cutting edge communications and marketing tools for a very small cost.

Outcomes

The arts allow for emotional engagement, which itself enables wider discussion of mental health and the ability to access audiences that otherwise would not engage with the issues. Importantly the festival creates artistically credible arts events and experiences and celebrates the relationship between mental health and creativity. In addition to the clear anti-stigma effect, the festival challenges inequalities in public mental health, encourages participation in arts to promote wellbeing and makes connections between organisations that might not meet.

The cultural impact has been high, with mainstream critics in national media praising the artistic quality of the event, as well as its goal. Major cultural activities such as the Edinburgh Festivals and National Theatre have approached and engaged with the Mental Health Arts and Film Festival.

The audience impact has been the subject of a mixed methods evaluation from the early days of the festival. There is a research consortium with academic, service user, health service and NGO involvement. The objective has been to contribute high quality, peer reviewed evidence of the benefits arts in mental health across a range of academic areas. This has led to publication in several high profile journals.

In general the festival has increased the positive mental health perceptions of audience members, as opposed to reduced the negative. Importantly the events have reached non-traditional groups, including a disproportionate

number of people on low incomes, from ethnic minorities and to some extent people with mental health problems. Co-programming with community events and using different genres allows reach to be extended further.

Knifton concluded by discussing the importance of using mixed methods of measuring and evaluating in order to triangulate the evidence. He was keen in principle to explore the potential for a network of mental health arts festivals on a European level.

DISCUSSION

David McCarthy (MadPride Ireland) felt that it was important that services themselves were demystified, because people did not appreciate what actually went on in services and therefore were susceptible to false impressions. These impressions could be compounded by the fact that mental health differed from other healthcare because there were circumstances where treatment for mental illness could be given without consent.

Ray Xerri (Malta) spoke about activities in Malta to reduce social stigma. The main psychiatric hospital holds public exhibitions for example of vintage cars or tropical fish which have a high public attendance. Hospital facilities such as the theatre are also rented to local community groups. The hospital has a structured programme for older teenagers to visit and engage with patients to reduce social stigma. This programme has been so successful that the hospital is now under pressure from the education department to further extend the programme to cater for the increased demand from schools

CHAIR

Johan TEN GEUZENDAM, Head of the Unit "Integration of People with Disabilities", Directorate General for Employment, Social Affairs and Equal Opportunities at the European Commission, chaired the parallel session on employment and meaningful activities as routes to recovery. He explained that the Unit is involved in moving forward the ratification of the UN Convention for the Rights of Persons with disabilities at the Member State level, including providing support to NGOs, contracting out studies and pilot projects. The EU Disability Strategy which will be presented on November 15th includes employment as one of its 8 main areas for action. He lead up to the first speaker by asking where there are hopeful signs in this area, as the employment statistics do not seem to be very promising at the EU and Global level.

SETTING THE SCENE:

Claire HENDERSON, from the Health Service and Population Research Department at the Institute of Psychiatry, King's College London, UK, introduced the topic of the session by pointing out the employment rate of people with mental illnesses (18-30%) is the lowest for any of the main groups of disabled people, and highlighting several underlying assumptions of employers which contribute to this problem. She outlined the aims and some findings from the 4 year Viewpoint survey (as part of the evaluation of the UK's "Time to Change" campaign) and the Shaw Trust surveys of employers in 2006, 2009 and 2010.

The viewpoint survey study found a drop in the number of interviewees who answered positively to the questions "have you been treated unfairly in finding / keeping a job?".

The Shaw Trust survey results are also positive, with increases found in employers' awareness of the presence of people with mental health problems in the workplace, awareness of risks and accommodations for employees with mental health problems. The improvements have mainly been found in issues which are beneficial to those already in employment with mental health problems, rather than those looking to get a job. The survey also found a decrease in the number of employers who think those with mental health problems should disclose their problems before they are employed. This has been in line with a recent legal shift represented by the UK's 2010 Equality Act, which replaces the Disability Reform Act of 1995 and prevents employers from asking pre-employment health questions *including whether applicants are disabled* except in specified circumstances:

- Determining whether applicant can be interviewed/assessed or will need adjustments for the interview/assessment
- Monitoring diversity
- Determining whether the applicant can perform the job (assuming reasonable adjustments would be made if needed)
- Whether the position requires experience of a health problem or disability

Finally, Dr Henderson discussed two economic options to reduce the stigma surrounding mental health problems in the workplace: Time to Challenge – an online resource for employers, employees and those seeking work, including videos to model good practice; Social contact interventions, such as "Well Business" in which senior managers and service users take part in a day-long meeting to discuss mental health issues.

PRESENTATIONS

Christoph LAUBER, Professor in General and Adult Psychiatry at the University of Liverpool, UK, presented the EQOLISE project and discussed the effectiveness of supported employment for people with severe mental illness. He started by giving an overview of the situation in Europe and pointing out the stark difference in rates of employment for those with mental and physical illnesses, despite a widespread wish to work on the part of

these people. He pointed to the lack of support currently available to enable those with severe mental disorders to access the free labour market, and the failings of the more widely adopted “first train, then place” model, i.e. a step-wise vocational rehabilitation in sheltered condition. Supported employment, through the Individual Placement and Support (IPS) approach, places vocational rehabilitation as an integral part of an individual’s care plan (and makes it so equally important to any other rehabilitation measure), and works through the process of placement first in a *real* job/position and subsequent training on the job, whilst employees and employers are supported by so-called job coaches, i.e. professionals who facilitate the process of vocational rehabilitation.

The EQOLISE project aimed to evaluate the effectiveness and cost-effectiveness of IPS for people with severe mental illness with long-term unemployment in a European context (following the proven success of this approach in the USA). The study was designed as a randomised control trial (RCT) and was conducted in cities in six European countries: UK (London), Bulgaria (Sofia), Germany (Ulm), Italy (Rimini), NL (Groningen) and Switzerland (Zurich). It aimed to compare IPS to vocational training on a number of relevant outcomes.

Findings of the study revealed that IPS, when compared to conventional vocational rehabilitation, is more effective in facilitating individuals’ return and staying in work; more cost-effective; and resulted in reduced hospital stays independent of previous medication and job preferences or consistency.

Terese DUARTE, from the President of the Board, Association for Psycho-Social Integration and Study – AEIPS, Portugal, presented the Association’s Supported Employment Programme, which is run in Lisbon. The mission of AEIPS is the recovery (according to an experiential definition) and social inclusion of people with mental illness experience through empowerment and community participation processes. As part of an individual’s self-determined recovery plan, AEIPS provides a service of support for employment in the free market, in any company in the Lisbon area. The association offers assistance with the different phases of finding and keeping work:

- Choosing a job – AEIPS assist with job matching and searching for companies
- Getting a job – help in contacting employers, developing a résumé and preparing for an interview.
- Keeping a job – assistance, where requested, with negotiating with employers, limited disclosure and arranging reasonable accommodations.

Dr Duarte also presented an alternative strategy to support employment – that of job site training. In this approach, a professional from a company acts as a tutor to the employee. The AEIPS team helps with accommodations while the employee works as an intern in a company on the open market and receives a grant for their work. In this way, the employee receives the natural sources of support provided by work, such as inclusion and participation in the workplace social environment, the company receives a free intern and the process also works to reduce stigma through social contact with a person with mental health problems. The association offers support and advocacy for an unlimited time, both in and out of work, with regular weekly meetings, as well as the availability for the company to consult them over any related issues. Very often, the internship leads to a contract with the company as a fully-paid member of staff.

AEIPS is also looking to start a new programme along the same lines to offer supported education at secondary schools and universities, which are frequent drop out points due to mental illness.

Dr Duarte concluded by stating that: “In the recovery paradigm, recovery is not about making people with experience of mental illness mainstream but extend the margins of the mainstream, to build a community that celebrates diversity and where all people can develop their talents and participate in equal terms, in economic, social and political life.”

Andrzej CECHNICKI, from the Jagiellonian University Krakow, Poland, opted to allow the session participants to hear about the community activities for users with severe mental illness in the service users’ own words, through videos of a performance art piece in an exhibition and interviews with several workers in the “cogito hotels” in Krakow. He presented an integrated educational program carried out in Cracow, Poland, by the Community Psychiatry Unit at the Jagiellonian University in cooperation with “Open the Doors” Association of Users. The

programme is conducted by psychiatrists, psychologists and other community psychiatry workers of Association for Development of Community Psychiatry and Care, as well as the Users themselves.

The Cogito hotels are one of the social firms which form a part of the Community Treatment Program (CPT), offered to those with mental health problems in Krakow. The hotels have the features of both a workplace and an educational centre. As a workplace each hotel offers the usual hotel services at a competitive standard in the open market. As an educational centre, the hotels host lectures or seminars, given by someone who has experience of mental health problems, for medical professionals and students. The professionals interviewed in the video talked about their experiences of mental illness and the important role that their employment had played in their recovery. Ten such TV films (each of 7 min) were made and shown on a regional TV programme.

The idea is to show the good practice of community psychiatry, activities of professionals and users and how they might be joined. The basic approach is to integrate treatment, rehabilitation and work; from Day Treatment Centre to sheltered work. The parallel step is co-operation with many institutions and associations in the town to involve local community.

The Anti – Stigma programme encompasses so far:

- the establishment of the Association of Users focused only on educational activities
- the foundation of Educational Centres in social firms – “U Pana Cogito” and Green Spot Hotels
- finding education target groups: students of medicine, rehabilitation, sociology and theology, teachers, journalists, students of secondary schools, priests
- organizing “Introduction to Psychiatry” classes for the first-year students of medicine, which are carried out together with the Users
- giving about 500 interviews in mass media and making 15 educational movies for Polish television
- “Dla Nas” (“For Us”), a magazine which is created, edited and published by users, families and professionals
- organizing The Annual Symposiums of Trialog, which concern psychosis and overcoming illness
- “Education through everyday contact” by everyday activity of Cogito Hotels and Green Spot Hotel.
- a special form of education is “Psyche”, a therapeutic theatre, performing “Summer Night’s Dream” at a well know theatre in Kraków; this performance about 500 students from secondary schools saw the play as the one of element of our anti-stigma program. In this way the students found that the use of creativity helps the patients to recover from their psychotic illness,
- painting exhibitions in the very famous Gallery in Krakow - “ Palace of Art” where artist shown their pieces of art together with outpatients paintings,
- spreading the idea of open psychiatry in education and TV productions, lectures on Symposium,
- preparing and coordinating the campaign of the “Anti -Stigma Program”,
- preparing “The Day of Solidarity with People Suffering from Psychosis” in Kraków
- psychotherapeutic and recreational camps which we have been working for 25 years now, (raczej wyrzuciC)
- the exchange with other groups of users f. e. from Germany and France

All these activities have two aims: the social inclusion of people with mental health problems and combating stigma.

DISCUSSION

In the remainder of the session following the presentations, several points were raised and discussed:

- It was noted that good practice such as that presented in the session was relatively rare, and that the establishment of a robust evidence base would strengthen political arguments for extensive supported employment and community integration.

- Sick leave policies are instrumental in both motivating return to work and protecting workers with mental health problems. The point was raised that sick leave covered at 100% can act to disconnect the person suffering from a mental illness from the workplace for a longer time, whilst graded sick leave promotes an earlier and gentler return to work. On the other hand, policies which deny sick leave to part-time workers (as in the new UK legislation) is not helpful to those with mental health problems who may need to work on a part-time basis.
- The question was raised of how to convince employers to take on an individual with mental health problems, especially in the current economic climate. However, the panel of speakers were convinced that placement in a workplace was not a major barrier (and even could be seen as a positive opportunity for companies). This is more challenging for higher qualified individuals, where the possibilities for supported employment are slightly more limited.
- It was highlighted that training and employment programmes need to match the skills and competencies of participants, rather than offer an opportunistic and limited selection of skills training which does not improve the individual's chances of gaining a job.
- It was noted that an important aspect of successful programmes was the offer of support to employers, not because they necessarily avail of it, but as a guarantee to overcome misconceptions about the risk of taking on an employee with mental health problems.
- Gaps in this field were noted in programmes and support for self employed workers (which is a common solution used by workers with mental health problems to gain the flexibility needed) and for workers or initiatives to improve inclusiveness in the public sector.

1730-1800 | PLENARY: FEEDBACK FROM THE PARALLEL SESSIONS

The session rapporteurs gave feedback to the plenary session:

Session 1: Kristian WAHLBECK WHO – Europe

Session 2: Sara EVANS-LACKO Kings' College London, UK

Session 3: David MCDAID London School of Economics, UK

TUESDAY 9TH NOVEMBER 2010

0900-1025 | PARALLEL SESSION 4: RIGHTS, RESPONSIBILITY AND CITIZENSHIP

CHAIR:

Professor **Jan JAŘAB**: Regional Representative of the UN High Commissioner for Human Rights, highlighted some of the complex issues in relation to mental health and the rights agenda. There was a need to consider both the rights of people with mental health problems in relation to care, treatment and restriction, but also those rights in relation to wider citizenship.

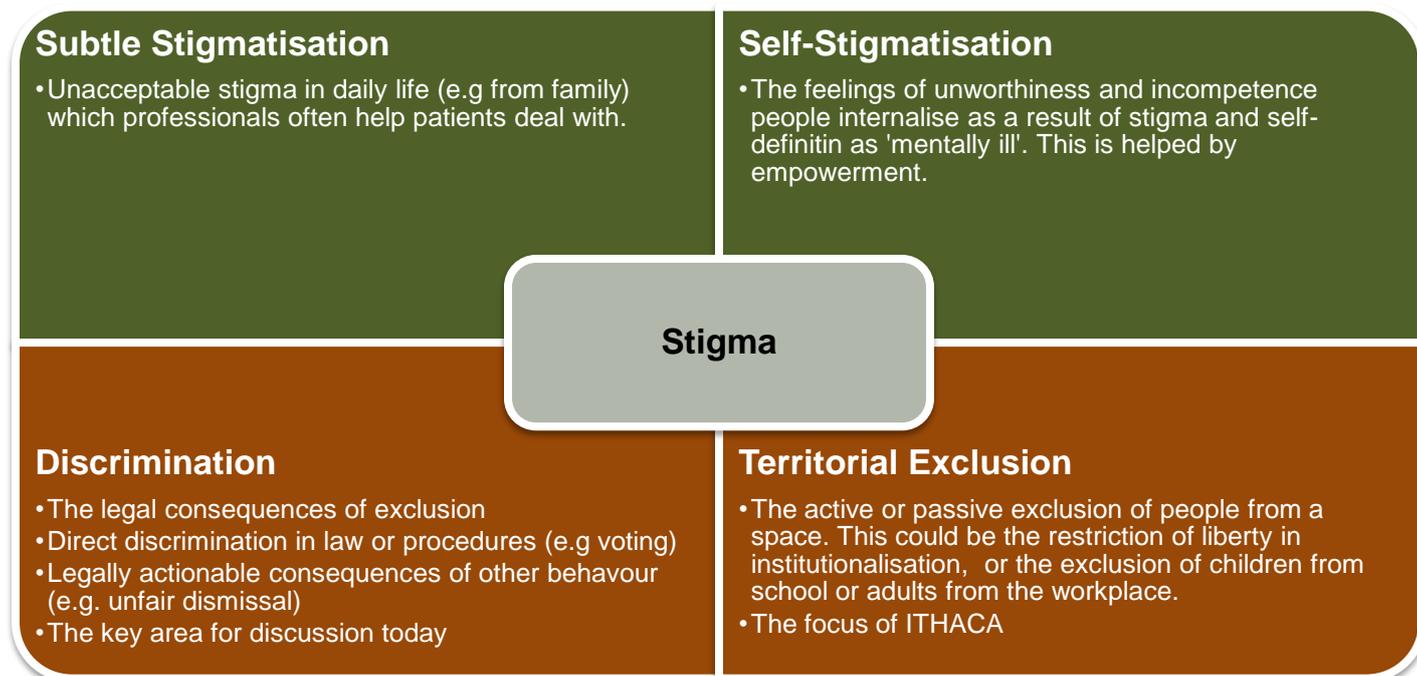
SETTING THE SCENE:

Professor **Heinz KATSCHNIG**, Ludwig Boltzmann Institute, Vienna, Austria, undertook to introduce the topic before discussing the ITHACA toolkit, an instrument for monitoring human rights and general health care in

mental health and social care institutions, developed in the EU Public Health Programme co-funded project ITHACA.

Professor Katschnig introduced three Es of human rights in mental health, initially proposed by Professor Graeme Thornicroft: **Evidence** – Evidence for action has become a key motif in recent years. There is an argument that in some quarters the need for evidence before action has become over emphasised. **Ethics** – The ethical basis for human rights is important, and this derives not from evidence but from politics and consensus. **Experience** – is critical, both the expertise of professionals but also expertise by experience...we are talking about Ethics and Experience.

Stigma and discrimination can be regarded as a second illness. Prof. Katschnig described four domains in which stigma operated:



Professor Katschnig described the milestones of human rights and mental health in Europe, drawing both on the UN Convention on the Rights of People with Disabilities and the foundation of the EU Fundamental Rights Agency. He urged participants to also be aware of work by the Council of Europe on a reference tool for human rights and ethics in mental health.

For many years the principle method of treating people with mental health problems has been in institutions, on a voluntary or compulsory basis. The EC has supported a range of project activities through both the Public Health Programmes and Research Frameworks which seek to improve quality of care and address rights and inequalities in institutional treatment. DEMOBinc and ITHACA, and work on forensic and involuntary detention are represented at this conference, with the EUNOMIA project on coercive treatment (<http://www.eunomia-study.net/>) and the HELPS Project on the physical health of people in institutional care (<http://www.helps-net.eu/>) also of key interest.

Project ITHACA (Institutional Treatment, Human Rights and Care Assessment) identifies and disseminates best practice to improve the protection of human rights and dignity and the general health status of residents in health or social care institutions with mental ill-health, mental disabilities or dependency. The project is led by the Institute of Psychiatry, and is co-funded by the EU Public Health Programme

One of the principle objectives of ITHACA was to establish a widely used useful method to assess good practice. This toolkit is intended for use in institutions to assess a range of factors relating to gene3ral health, human rights and dignity of patients in residential care. A research team of 44, including 15 service user researchers conducted service user focus groups in 15 countries. This helped prioritise the key areas for assessment, which were then tested in four centres. The toolkit was then field tested in 87 institutions in 15 Member States. The

Toolkit has a comprehensive, accessible process and accompanying information. The final version has been refined to 30 prompts for each visit.

The toolkit is being translated in to 12 languages, and is ITHACA toolkit is downloadable now from www.ithaca-study.eu/results

PRESENTATIONS:

Dr. **Mario OETHEIMER**: Programme Manager, European Union Agency for Fundamental Rights, gave a brief overview of a new Fundamental Rights Agency (FRA) report on the right to political participation of persons with mental health problems and persons with intellectual disabilities.

The FRA was established to provide evidence based advice to EU institutions and Member States. This report was produced as part of a wider project looking at fundamental rights of persons with intellectual disabilities and mental health problems which is ongoing. A social study is underway, in tandem with legal analysis. The final socio-legal comprehensive report will be published in 2012.

In terms of participation in the democratic process, Dr. Oetheimer described a great variety of approaches in the legislation of the EU Member States. This came somehow as a surprise since the right to vote is guaranteed by the universal declaration of human rights and subsequent international and European treaties. The right to political participation is protected by Art. 29 CRPD. The CRPD requires an effective participation, that is not only to provide the right to vote and to be elected. Article 29 calls on Member States to organise and support persons with disabilities to participate in the voting procedure. A recent case handed down by the European Court of Human Rights (A. Kiss v. Hungary; 20 May 2010) was discussed. In this case the applicant, who was under partial guardianship, was automatically excluded from voting. The European Court found a violation of Article 3 of Protocol no 1 to the ECHR since only an individualised judicial evaluation could have legitimised the applicant's voting right restriction.

The FRA report discusses a 'participation spectrum' which ranges from the total exclusion of people with mental health problems to vote and to stand for elections, to a full participation, where people with mental health problems are able to stand for elections and to vote. A large number of Member States fall somewhere in the middle: a individualised assessment is performed either by a judge or medical professional.

For some countries, the constitution rules one way or the other, dictating either exclusion, full participation or a middle ground such as individual assessment. In other countries the "participation spectrum" is to be found in the legislation.

Not all countries legislation are aligned to the CRPD, and as a result many are now reassessing their constitutional provision (such as the Netherlands) or their legislative provision (such as Slovenia). Other countries try to accommodate the persons' needs. In Denmark assistance is available for voters with disabilities on election day, and in Finland there is the possibility of patients in hospital to vote in advance by post. Notwithstanding these positive signs, the FRA has found that a gap still exist between the standards in place and their implementation at national level.

Professor Hans-Joachim SALIZE: Central Institute of Mental Health, Germany, addressed the question: "Detention of Mentally Ill Persons in Psychiatric Hospitals, Forensic Institutions or European Prisons - is it appropriately regulated?". Professor Salize referenced three studies undertaken for the Public Health Programmes which discussed the appropriateness of the regulation of compulsory treatment, forensic care and prisons (1999-2007). Recognising that these studies were now becoming dated he was keen to make the central point that we must see and acknowledge the interaction and relationship between forensic psychiatry, prison and general psychiatry. It is clear that such a relationship is complex, and further work on these links is desirable. Having available continuously updated data on the issue from all Member States is crucial.

Civil Detention

Involuntary placements are rising across EU. Many conclude from this that coercion is rising, but in Dr Salize's opinion this isn't so clear. Comparing involuntary admissions with all admissions we see that the percentage of admissions that are involuntary has remained stable across the EU as a whole. Notwithstanding this there is huge variation between Member States.

- The criteria that can be used to justify involuntary detention vary. Most involve one or both of the threat of danger to self/others and the need for treatment. When the emphasis is on perceptions of danger more men tend to be detained. When the emphasis is on treatment the gender balance is more equal.
- Mental health laws don't always specify mental disorders, and often use outdated language or theoretical underpinnings.
- Most laws don't draw distinction between involuntary detention and involuntary treatment.
- Independent advocacy on behalf of patients is missing in law in 60% of EU Member States.
- The method of assessment of mental state and the professionals who can detain people varies, as does the length of initial detention. Some countries require a mental health professional or multiple mental health professionals to assess. Other countries require just one doctor. The initial placement order can vary from 2 years to less than a week.
- Compulsory outpatient treatment is mentioned in law in 26% of Member States, as a least restrictive option. This is an issue which is strongly debated by user groups.

Forensic

Professor Salize reported a slow but steady increase in forensic psychiatry referrals. There is some concern amongst forensic psychiatrists that this increase is explained by a reticence amongst community psychiatrists to manage complex cases that may involve some forensic aspects.

The availability of dedicated forensic psychiatry beds varies immensely across Europe. Almost all countries have to rely on general psychiatry and prison placement of mentally disordered offenders. Forensic outpatient care is not available in the majority of Member States, and the maximum pre-trial placement is not specified in many countries. Some countries are addressing these difficult issues as they review and reform mental health law.

Prison Populations

Prison places vary across Europe, with a tendency of east Europe to provide more prison places. Many prisons are seriously overcrowded, especially in those countries with less capacity. This increases risk factors for mental ill health and suicide amongst the general prison population. Availability of indicators at the primary and secondary levels is poor for prison populations. Suicide is the only broadly comparable indicator. Mental health service indicators such as prescription rates of medications that are available in general populations are often not available for prison populations.

Professor Salize concluded that a settled solution for all stakeholders was unlikely for the complex relationship between prison, forensic care and involuntary treatment, because of the constantly contradicting views. Instead he called for a constantly reviewed balance between safety, dignity and rights, and quality treatment to be maintained.

Professor **Miguel XAVIER**, from the Ministry of Health and Universidade Nova de Lisboa, Portugal, asked the key question "How effective is mental health legislation in effecting change in the real world?", and sought to use Portugal as an example of the answer.

New mental health law was passed in Portugal in 1998, which covered compulsory treatment and introduced multi-disciplinary mental health teams. There is a judicial model of detention, with courts and health services working together. The patient has rights to legal support, and to attend all sessions. Compulsory admission has to be reviewed by the court every two months.

The profile of services is improving, though inpatient care still uses some 83% of the available resources. The compulsory treatment sections of the law work well, but the other parts have lagged behind and a review is under way.

The challenge is the legislation gap between the civil code and the mental health legislation. This must be addressed going forward as there are differences between the CRPD, which Portugal has signed, and civil codes that say for example that people without capacity cannot vote.

Professor Xavier proposed a three point 'Recipe for Change' in mental health law implementation:

1. Law should not be static. Regular revision and updating is essential.
2. Strong political support is essential. Without political backing change is impeded.
3. There need to be strong pressure from user/carer lobby, to put the case, and encourage political momentum.

DISCUSSION

John McCarthy (MadPride Ireland) stated his opposition to the compulsory treatment. He cited an example that in Ireland the initial period of detention allows 20 days of treatment that in the case of ECT or strong medications can change a person forever. He called for greater transparency in tribunals and other bodies which determine care plans, and stronger involvement of users of services and representative.

Ann Laure Donskoy (ENUSP) asked Professor Salize whether his data were still valid given their age. **Professor Salize** accepted that the data were slightly old, although all concluded trends and tendencies are still valid. He cited the fact that newer data were unavailable as being symptomatic of the neglect of these issues by research and routine health reporting.

Chris O'Sullivan (Scotland) asked the panel if they felt that stigma was assisted by a public misunderstanding and even acceptance of sometime outdated legislation that described the need to detain and treat 'dangerous' individuals. He agreed particularly with Professor Katschnig's point on territorial stigma, because addressing this would have benefits not only for people with mental illness but also the wider population.

Constantinos Moskovakis (Ministry of Health of Greece) was interested in the potential for a hierarchy of rights, since fundamental rights like the right to vote was different to other rights. He felt that implementation of core rights could then be followed by work on others. Mr X also called for systematic collection of data on difficult issues for example on restraint.

CHAIR

Manuel GOMEZ-BENEYTO, Professor of Psychiatry and Coordinator of the Spanish NHS Mental Health Strategy, opened the session as chair by highlighting some of the key issues in this area. He stated that effective comprehensive care is a precondition for social inclusion, but that institutional psychiatric care (in psychiatric hospitals) still dominates in Europe. He ran through the three conceptual steps in the process of psychiatric reform: from the asylums (where the needs of the inmate were defined by the institution) → psychiatric hospitals → community mental health systems → adoption of the recovery paradigm (where the individual's needs are defined by the users themselves and their carers). Dr Gomez-Beneyto pointed out that each step leads to an increment in the empowerment of the patient. He defined comprehensive care for people with mental health problems as: a system of care concerned with satisfying the mental health needs of a geographically defined population, which is composed of a coordinated network of services including Primary Care, Social Services, Employment, Education and Justice sectors, as well as users and their carers and the Third Sector (NGOs and volunteers), which delivers integrated interventions based on evidence, experience and values and is guided by the principles of recovery.

SETTING THE SCENE

Helen KILLASPY, from the Department of Mental Health Sciences, University College London, UK started by explaining the rationale for focusing on institutions, despite the long-term goal of community care, in stating that two thirds of mental health “beds” are in hospitals, 50% of people suffering from mental disorders are treated in large institutions and there is an ongoing process of reinstitutionalisation (with beds being moved to smaller hospitals and forensic settings). She argued that institutional care could also be recovery-orientated and that quality of care is key in challenging stigma, addressing human rights violations and improving social inclusion.

Dr Killaspy presented the Development of a European Measure of Best Practice for People with Long Term Mental Illness in Institutional Care (DEMoBinc). The aim of the DEMoBinc project was to develop a methodology for the assessment and review of the living situations, care and treatment practices in psychiatric and social care institutions for mentally ill and disabled persons in the European Union, with a particular focus on human rights, the protection of the dignity of residents, the use of restraint and the scope for health promoting measures. The project has developed a toolkit to assess quality of care in countries at different stages of deinstitutionalisation, which is based on a “recovery model” framework, is relatively brief to administer and is designed to be used by a unit manager. The toolkit provides ratings of the quality of a unit on seven domains: living environment; therapeutic environment; treatments and interventions; self-management and autonomy; social interface; human rights; and Recovery based practice.

Dr Killaspy outlined the development and methods used to refine the toolkit. Items included were identified from a review of care standards in each of the ten countries that participated in the project, a systematic review of the international literature on the evidence for different components of care for people with longer term mental health problems, and a Delphi exercise with service users, carers, clinicians and advocates in each country. The toolkit was tested for its inter-rater reliability in 20 units in each country and validated against the experiences of service users in these institutions. An international expert panel provided further review throughout the project to ensure that no areas of care were neglected. A health-economic analysis was also undertaken to assess the units’ “value for money”. One interesting finding from this was that, while there was much variation in the costs of care in these units across different countries, costs did not particularly relate to quality of care.

Finally, Dr Killaspy how the toolkit has been further developed as a web based resource, the Quality Indicator of Rehabilitative Care (QuIRC www.quirc.eu). It is completed by the unit manager in approximately 45 minutes and produces a printed report of the results for that unit that shows the unit's % performance on each of the seven domains of care compared with similar units in the same country. The QuIRC is currently available in 10

European languages (Bulgarian, Czech, Dutch, English, German, Greek, Italian, Polish, Portuguese and Spanish).

PRESENTATIONS

Lucie KALIŠOVÁ, from Charles University in Prague and the Czech Psychiatric Society, Czech Republic, started by giving an overview of the situation in the Czech Republic, including the systems of care, usual pathways and types of institutions. The majority of care for mental health problems is provided in large complexes (psychiatric institutions), with some community care found in the big cities, provided by NGOs on a small scale. The reason for this is the low level of funding dedicated to psychiatric care (3% of the total health budget).

Dr Kališová went on to discuss the assessment of the quality of care in the country. This is rather patchy and not carried out on a regular basis, although it includes visits to psychiatric hospitals by Ombudsman office representatives, Ministry of health programmes and an accreditation process by Common Accreditation Committee. Next she discussed the achievements and activities of the Czech Psychiatric Society, which include the setting of care quality as a priority and pushing for the development of community services. The Society has also carried out dissemination and implementation of the QuIRC tool at the national level by translating the toolkit, presenting it at conferences and specific training meetings for psychiatric hospitals, at the Ministry of Health and the Ombudsman's office and by providing a link on the Society website.

Angelo FIORITTI, Director of the Department of Mental Health and Substance Abuse, AUSL Bologna, Italy, presented the case of the region Emilia-Romagna in the development of comprehensive community mental health services, after the large psychiatric hospitals were closed in 1997. He explained that these are the services which aim to improve mental health and well-being, to promote social inclusion and to combat stigma. The project is based on the 2009 Regional Mental Health Plan (DGR 313/09), which follows 3 main guiding principles: Availability, accessibility and acceptability.

Services are considered available and comprehensive if they are community based, provide coordinated adult/child mental health, addiction and social care, and provide support in housing or employment. They should also include prevention, promotion and self help activities. Accessibility was linked to the provision of sufficient community-based resources, a proactive focus and the enhanced role of primary care. Finally, accessibility was described in the context of a human rights approach, which includes the empowerment of the population, the promotion of active participation and different types of work with the community. A number of these activities were also described, such as anti-stigma campaigns or new local approaches.

Ray XERRI, from the Ministry of Health, Malta, introduced the new Maltese Mental Health Act, which is now under revision by the national parliament and is expected to come into law in early 2011, with a specific focus on issues related to community-based care and human rights.

As a starting point a number of guiding principles were described, related to the rights and obligations of people and also the Government. The Law is client-centred and is intended to counteract stigma and to protect clients from abuse. The promotion of social inclusion and the provision of effective treatment in the shortest time possible are also among its main aims. According to this Act, clients would have a number of rights, such as the provision (in the majority of cases) of information on their diagnosis, to participate in treatment plan or to receive good quality treatment, rehabilitation and aftercare in the least restrictive environment. Decision taking on the protection of rights is expected to be split among clients, professionals and the Commissioner for the Promotion of Rights. This newly-established figure would act on a proactive basis, monitoring care of involuntary treatments and also those people under official guardianship or tutorship. The high level of efficiency of treatment would be based on the development of detailed disciplinary care plans, the coordinating role of case managers and also on professional accountability. If the plan is not stuck to, the Commissioner can take appropriate actions against any defaulting professional. A number of measures were also described to protect clients from abuse, such as

the distinction between mental faculty and capacity, with an independent review to certify lack of faculty, or the restriction placed on health professionals to act up to the 3rd generation of their own clients.

DISCUSSION

Following the presentations, several points were raised and discussed:

- With regard to the Maltese Mental Health Act, the question was raised as to whether this had been found to be compatible with the UN Convention on the rights of Persons with Disabilities, in particular in safeguarding against bad decisions by the individual in the post of Commissioner. It was noted that the plan had undergone a broad consultation before the Law was developed and that the Commissioner will be assisted in his work by a task force.
- It was commented that quality of care indicators should be targeted at different diagnoses and services or that ideally, cross-cutting indicators should be established, but that at present the parsimonious response is to adopt indicators for the quality of care received by those *most likely* to be in long-term care.
- It was highlighted that whilst Member States such as Czech republic may not yet be at the stage of deinstitutionalisation, this is the overall goal of relevant organisations, such as the Czech Psychiatric Society. Barriers to this transition that were highlighted were the complexity of the political decision (including financial considerations) and the lack of an informational “floor” or monitoring system to allow the exchange and availability of information to run community services (as is seen in the Emilio Region, Italy). On this second point, it was also noted that the monitoring and information system took some time to establish, and is better in some areas (e.g. substance abuse) than others (child and adolescent mental health). It was also noticed that it was important to have consistency between regional and national systems to ensure seamless transfer of data.
- It was stressed that the tools such as the QuIRC were not intended to detract or reduce the momentum towards deinstitutionalisation, but were necessary in the current situation where care in so many member states is characterised by large long-term institutions.

1045-1105 | FEEDBACK FROM THE PARALLEL SESSIONS

RAPPORTEURS:

The session rapporteurs gave feedback to the plenary session:

Session 4: Marta FERRAZ (Ministry of Health, Portugal)

Session 5: Ionela PETREA (Trimbos Institute, the Netherlands)

MODERATOR:

The session Moderator, **John BOWIS**, Former Member of European Parliament for London spoke of his deep personal and professional loathing of stigma as problem that must be removed from the health service. Stigma further complicates mental health problems themselves. Bowis described stigma is a human rights abuse; often unintentional, but damaging, It is “literally prejudice, ignorant assumption and emotion”.

Mr Bowis called upon panel members to briefly suggest ways in which principles can be converted into practice, and started discussions with some reflections of his own:

- We need to listen more to people with lived experience. We need responsible authorities to require the involvement of service users in planning their own care and treatment.
- Just as we acknowledged and tackled institutional racism in our society, we need to do the same for stigma.
- We need to bring together all the agencies and policies, and not just the obvious ones. We need employers to have to report annually on their mental health work as part of their compliance with health and safety law.
- We can't be limited by treaty competencies. We need to think laterally, draw up plans and allocate actions that are carried out

DISCUSSANTS:

Ms **Josee VAN REMOORTEL**, Senior Policy Adviser to Mental Health Europe (MHE) thanked the EC for the opportunity to open the discussion, echoing Mr. Bowis by confirming that the problem of stigma and discrimination is at the heart of MHE.

Ms Van Remoortel reported on the recent MHE Conference on 'Breaking the Cycle of Mental Health and Poverty'. The key recommendation from that event was that poverty and actions to address poverty should be a key part of anti-discrimination activities in mental health. The example was cited of children in more deprived areas being more frequently more institutionalised than other areas. Ms Remoortel pointed to the fact that poor people and those in isolation don't have the social networks and access to improve their mental health. They also do not necessarily have the financial wherewithal to buy services where they aren't free.

Ms Remoortel suggested three actions:

1. National Focal Points for mental health should be mobilised to assist with this agenda. We should urge them to ratify CRPD and other human rights frameworks, and then to emphasise need to support reform of law/practice to assure implementation.
2. User empowerment programmes should be developed and implemented with the aim of encouraging people to take and advocate for their own decisions.
3. DG EMPLOYMENT anti-poverty and equal opportunities work should continue to develop connections to mental health. Employment and opportunities for involvement are critical to recovery both for people with mental health problems, and for the wider economy.

Professor **Jose Miguel CALDAS DE ALMEIDA** represented the Ministry of Health of Portugal in the discussions, and reflected on what he had what most valued and had learned through the event:

With regards to **stigma**, there were four key points. Firstly was the need to focus on behaviour and the discrimination which is the damaging aspect of stigma. Secondly was the need to maximise the involvement of users and carers in planning and delivering stigma activities. These activities should be locally tailored,

potentially with some national support. Improving the quality and accessibility of mental health services is critical to anti-stigma interventions,

On **service improvement**, Professor Caldas de Almeida pointed to the need to ensure that “beautiful policies become beautiful practice” ensuring that gaps in provision are identified and addressed. Good quality indicators, and tools such as the ITAHAC toolkit and DEMOBinc tool look promising to help with this. Service design and delivery needs to be informed by evidence, and therefore health and population research including, but not limited to neuroscience continues to be vital

On **Human Rights**, the critical instrument for achieving change is the Convention on the Rights of Disabled People. The level of human rights literacy in mental health services is likely to be low, and one step could be to ensure professionals are aware of CRPD. Finally, the process of developing the Convention included disabled people at every stage. There is much to learn and incorporate about involving service users and carers in this work, ensuring that their distinct perspectives are separated.

Finally, Professor Caldas de Almeida pointed to the importance of good **mental health legislation**. The creation of good legislation is a good opportunity to discuss mental health at the political and societal level, and implementation and subsequent regular review can continue that dialogue.

Dr **Jan JAŘAB**, Regional Representative of the UN High Commissioner for Human Rights, identified two key challenges which he believed must be addressed to improve human rights in mental health:

1. The human rights of mental health service users must be made much more visible in the human rights community as a whole. The rights of those with mental illness should be mainstreamed the rights in human rights structures, including the UNHCHR.
2. Human rights should play a more prominent role in the design and delivery of services. We recognise that we cannot remove stigma without changing the way services are designed and delivered. There are different paces of change across Europe but we need to say clearly that we move away from the institutional model and towards community based services.

Mr. Jařab suggested three sets of recommendations for different stakeholder groups:

- **To representative group:** Mr. Jařab urged users of mental health, children, elderly and other disability services to tie empowerment narratives together, to look cross-sectionally at problems and work on some of the factors that allow institutional care to perpetuate itself.
- **To the European Commission:** Mr. Jařab felt that there is still space for improving consistency of policies by different commission DGs. These events have been useful in bringing SANCO and EMPLOYMENT together. However, budgets in other areas have often used to build or renovate large institutions of ‘care’, fortunately DG REGIO now starting to address this. The EC cannot support Member States in renovating a system that should have been reformed.
- **To Member States:** Mr. Jařab pointed to a key piece of legislation, the draft non-discrimination directive presented in 2008. He encouraged the EC to keep pushing for the directive, and urged Member States to stop blocking it. He urged all stakeholders to advocate for the inclusion of mental health in the directive.

Mr. **Michael HÜBEL**, Head of the Health Determinants Unit, Directorate General of Health and Consumers, European Commission, spoke of the growing importance of mental health in the cross cutting policy discussions at a European level. Without necessarily referring directly to mental health the issues are present for example in discussions about the future of GDP and social exclusion, One of the core objectives of the Pact is to pave the way for involving mental health across the board. Mental health is not the property of the medical professions; it has to be the issue for everyone.

Key activities for DG SANCO in this regard would be around sustaining the progress made, both with involving other policy areas and ensuring that political momentum and partnerships are sustained above and beyond the

five conferences. Finally there is scope for the EU Compass Database of good practice and policy to develop, and become widely known. Health is becoming an issue of interest when the EU is in collaboration with non-member states, which bodes well for the future.

User involvement is a challenge to which DG-SANCO is prepared to rise. Mr Hübel invited discussion to explore user involvement, to bring people in more productively.

Dr. **Matt MUIJEN**, Regional Advisor for Mental Health, WHO Regional Office for Europe, had three key reflections on the event. Firstly, he had learned from a number of people that we need to know more; to be able to compare across countries. Showing differences between countries is very important, because comparison can be a driver for change. There is potential to quantify and elucidate diversity, and international measures such as the WHO Helsinki declaration have helped to trigger this work.

A recurring theme of the most interesting presentations had been they were for activities that were alternative, holistic, and involving people. It was the involvement and meaning given that was useful. In most cases there was a local champion with energy and vision that pushed it, and then made it happen. We should do more to 'feed' these local champions, and Dr. Muijen pointed to the need to close big gaps between WHO and Member States, and then between government and the local beacons that make the differences.

A final theme was the noticeable lack of power and influence of the user movement. The user voice can often be marginalised, and it can be left to professional like social psychiatrists who are far removed from grassroots realities. Often people participating in events have to balance different interests, and sometimes for professionals, that means relating user views is reprioritised. Achieving service user influence is genuinely hard when the movement is fragmented, dissipated, and not resourced to be able to act. Dr. Muijen called for a shift of resources, with a key action from this event being realistic funding and support of user movement.

Ms. **Mary NETTLE**, former chair of the European Network of users and Survivors of Psychiatry (ENUSP), thanked the EC for the opportunity to contribute, and for the poster presentation explaining ENUSP's work. She summarised the mission of ENUSP as being "to try and get institutions and others to do the right thing by service users."

She pointed out that it was exceptionally hard for user representatives to participate in policy processes when they are often unpaid, unemployed volunteers who do not have the financial resource to pay for travel and subsistence even if it will be reimbursed. This was well illustrated by the fact that ENUSP has just had its first General Assembly for six years in Thessaloniki. Funding restrictions have kept the organisation from the benefits both that regular members meeting bring, and which improve validity and accountability in the eyes of funders. Ms Nettle emphasised the point made by Dr. Muijen, that user organisations are often given goodwill, but what they need is more practical support. When looking for experts at a national level, users groups must be there, because they are different experts with valid expertise.

Ms. Nettle pointed to the CRPD as being critical to the rights and empowerment of people with mental health problems. She reminded participants that the EU was part of the negotiation on CRPD, and called on the EC to ratify the convention, and to support Member States to ensure their legislation was consistent with the Convention.

Ms. Nettle referred to the breadth of opinion about services and mental ill health in the user movement. She spoke for example of compulsory detention and treatment. Within the movement there are people who feel that they want places of safety where they can receive support if they want it. When considering the refusal of treatment, Ms. Nettle drew the distinction, not often recognised in law between those people who refuse or wish to refuse treatment logically and with capacity and those that don't have capacity. Ms. Nettle was asked about the position of mental health within the disability movement. She referred to the value to others of the collective knowledge that people accrue through living through episodes of illness including the non-invasive strategies for assistance and self-directed recovery.

DISCUSSION

Professor Arne Holte (Norway) strongly endorsed moves to move the focus from stigma and attitudes to behaviours and discrimination. It is easier to monitor the effectiveness of anti-discrimination measures, and this approach has the additional benefit of moving the emphasis from the stigmatiser. He added that the conference had been very focussed on individual level actions, when the actions that were mostly likely to effect change were at a national level. He pointed to labour market policy, an area governed by labour and finance ministries as being critical. Because of the effect of the recession it is likely that people who are vulnerable or far from the labour market will be pushed out first and suggested that governments should use the state economy to create and maintain jobs for these groups.

Britta Baer (European Health Managers Association) announced the launch of a new Mental Health Systems Network, which would bring together managers implementing evidence in mental health. This network was due for launch in Brussels in early December.

John McCarthy (Mad Pride Ireland) felt that it was important to involve the most excluded people with mental health problems; those who have been the most let down by society, and subjected to the worst discrimination. They are living on the streets, not speaking in conferences or user groups. The representatives we hear from are the ones that did well in the system and recovered. It is possible to engage the most excluded vulnerable people in the policy process. Mr. McCarthy gave the example of the Murphy and Ryan reports in Ireland which looked into abuse in Catholic schools and institutions. These enquiries sought out and engaged the most excluded least articulate people who had been subject to abuse of their rights and person.

Lise Jul Pedersen (Denmark) shared her own feelings about recovery. She defined recovery as being about regaining a valued role in society. She placed the value of this above any medicines or services. Pathways to education and lifelong learning for people with mental health problems are important in finding that valued role.

Jan Pfeiffer (Lumos) urged the conference to remember that children often stigmatised by MH services. He pointed to cases when services for children are used to pathologise social problems of societies or families.

John Halloran (European Social Network) felt that the key was in supporting local level innovations. To really implement local change it is necessary to bring people together on a local level. There are some excellent examples of activities at a local level, but we need to find a way of expressing this local action at a European level. The Europe 2020 and Platform Against Poverty and Social Exclusion need to get sub-Member State level. One way forward to be to include regions in the expansion of the Open Method of Coordination.

Lee Knifton (Mental Health Foundation) felt that stigma and discrimination was ultimately about power imbalances. We need to examine language and methods to engage the most people. Toolkits, databases, good practice etc are quite technocratic terms, which are quite intimidating to those outwith the EU level policy sphere. We should be willing to use different social and cultural modalities to bring in more people.

Maria Jesus San Pío (FEAFES) expressed concern about gender issues being underrepresented in the agenda, and asked the EC to keep in mind the gendered approach when taking action forward.

Mary Nettle (ENUSP) spoke about one of the effects of mental illness being the tendency to become a victim of illness. We learn that we can't do things for ourselves because we are ill. This makes people likely to say we can't because of the systematic put downs.

Professor Manuel Gomez-Beneyto (Spain) said that too many messages can inhibit actions, and that we should pick the top few actions to concentrate on. With that in mind the best way to fight stigma and the top recommendation is to treat people properly in comprehensive community-based services that don't become the new institutions.

Mr. **Jürgen SCHEFTLEIN**, Technical Officer responsible for Mental Health at the Health Determinants Unit, EC, closed the conference by thanking all the participants for the inputs they had made. He particularly thanked Professor Gomez-Beneyto for suggesting such a concrete proposal for a priority. One of the key challenges in this topic area has been to acknowledge the complexity of the issues whilst still achieving a balance of social policy context and practical examples.

The future for mental health work at an EU level is encouraging. Well-being beyond GDP is likely to play a key role, with the European Foundation for the Improvement of Living and Working Conditions. DG Economics and Finance (ECFIN) have also shown interest in measuring softer indicators of subjective wellbeing. The key task moving forward is to ensure that evidence and practice can be brought to the table to speed up these processes and their outcomes.