

**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.**

**INVITED PAPERS:**

**EU PROJECTS ON PROMOTING SOCIAL INCLUSION  
AND COMBATING STIGMA FOR MENTAL HEALTH**

Invited paper for the thematic conference:

## **Announcing the new European Toolkit to monitor Human Rights and General Health Care in Mental Health Facilities**

### **What is the ITHACA Toolkit?**

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

### **Strong service user participation**

In developing the ITHACA Toolkit service users were consulted and employed at all stages. Over 100 service users participated in the focus groups which were conducted in each country. A key component of this consultation was to build service user capacity and involvement. In Finland, for example, eight service users were involved in conducting monitoring visits and testing the usefulness of the toolkit. As one of the service user researchers from Finland says: *“The experience has been very rewarding and we have learned a lot. The starting point was to combine human rights monitoring with trying to have an effect on developing the services as well...I am even more convinced that it is really necessary to have users monitoring, evaluating and researching”*.

### **The need for the ITHACA Toolkit in Europe**

People in mental health institutions across Europe too often remain out of sight, with poor monitoring to assess the human rights and general health care of their residents. Such people are an extremely vulnerable population to neglect or abuse in relation to their basic necessities of life as well as their civil and political rights. The international community took an important step forward in securing and protecting these rights in passing the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) in 2006, which places the responsibility for meeting the needs of all people with disabilities (including those with mental disabilities) on society. Persons with disabilities are not *objects* of charity or welfare but *actors* with rights. Governments and societies need to create environments which encourage and enable vulnerable persons to assert their right to health, education, civil liberties and the protections afforded in international human rights documents. Examples of key issues that have been identified in our testing of the ITHACA Toolkit include: access to and involvement in the development of care plans, correspondence and visitors, and movement of treatment into the community. The Toolkit fully supports the aims of the European Pact on Mental Health and Well-Being, especially the Combating Stigma and Social Exclusion thematic priority area.

## **Role of the EU in promoting human rights and general health care in mental health institutions**

All members of society have a role to play in the protection, respect and fulfillment of human rights and in putting into practice the right to health of people with mental disorders and related disabilities. Human rights are core values of the EU. EU can:

1. Support member states to promote human rights in spirit of the CRPD to enable all member states to sign and ratify the CRPD
2. Encourage members states to develop, use and improve monitoring systems with input and development from service users
3. Involve service users in all planning, implementation and evaluation of all Community actions of relevance to service users
4. Give policy support that promotes the full observation of human rights and the provision of good quality general health care, for example by the progressive development of community based services, consistent with the 2005 Helsinki Mental Health Declaration and Action Plan for Europe.

## **Language versions available**

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

## **Contact details and additional resources**

For full details of the ITHACA Toolkit please go to our website at <http://www.ithaca-study.eu/>, or contact Graham Thornicroft at King's College London [graham.thornicroft@kcl.ac.uk](mailto:graham.thornicroft@kcl.ac.uk).

For more detailed background go to:

1. Convention on the Rights of Persons with Disabilities (<http://www.un.org/disabilities/>)
2. Mental Disability Advocacy Centre (<http://www.mdac.info/>)
3. European Network of (ex-) Users and Survivors of Psychiatry (ENUSP) (<http://www.enusp.org/>).

Invited paper for the thematic conference:



*DEMoBinc*

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

### Summary of the Project



#### Overview

The DEMoBinc study (Development of a European measure of best practice in institutions for people with longer term mental health problems) was a three year collaboration across ten European countries (UK, Germany, Spain, Bulgaria, the Czech Republic, Italy, Poland, The Netherlands, Greece and Portugal). The study was funded by the European Commission and sought to develop a toolkit which could assess the quality of care in longer term mental health facilities, both those based in hospital and in the community. The final product of the project is a web based tool called the Quality Indicator for Rehabilitative Care (QUIRC) which assesses the living conditions and care that a unit provides and the degree to which it promotes the human rights and social inclusion of its residents. The QUIRC is a self-report tool completed by the unit manager. It uses a computerised algorithm to produce individualised, printed reports which detail the unit's performance on seven domains of care (living environment; therapeutic environment; treatments and interventions; promotion of service users' self-management and autonomy; promotion of service users' human rights; promotion of service users' contact with family and community/social inclusion; the degree of Recovery based practice) and the results for similar units in the same country are also shown for comparison. Further text provides more detail about the results and the areas of care the unit could focus on to improve their results.

This report provides a summary of the project and suggests that the QUIRC has potential for use across Europe as a routine quality assessment tool.

## **Background and context**

Individuals who reside in hospital and community based mental health units have longer term problems such as schizophrenia, schizoaffective disorder and bipolar affective disorder, complicated by poor response to medication, cognitive impairment, “negative symptoms” and other problems such as substance misuse. The complex nature of their problems makes it difficult for them to return home after admission to hospital and they continue to require a high level of support. Their problems can also make them vulnerable to exploitation and abuse by others and they may have difficulties in participating actively in choices about their treatment and care. The European Commission has given high priority to improving the quality of care of people with mental health problems through its Green Paper Improving the Mental Health of the Population - Towards a Strategy on Mental Health for the European Union, and through the European Pact for Mental Health and Well-being. The UN Declaration on the Rights of Persons with Disabilities enshrines the principle of services actively involving patients in their care and in the development of services (“Nothing about us without us”). However, for this group, this can be difficult to achieve and it was therefore a primary aim of the DEMoBinc study to include service user and carers actively in the development of the toolkit and to ensure that it was able to deliver assessments of the quality of care that reflected service user experiences.

## **Development of the toolkit**

The first stage of the project was to identify the components of care considered most important in longer term psychiatric and social care units. This was done through collating evidence from i) a systematic review of the international literature, ii) a review of national or regional care standards in the participating countries iii) the results of an international Delphi exercise. Four stakeholder groups (service users, carers, mental health professionals and advocates) in each country participated in the Delphi exercise which asked “what in your view most helps recovery for people living in institutions?” The results from all three sources identified nine domains of care which were agreed by the consortium partners and a panel of international experts: living environment; therapeutic environment; treatments and interventions; self-management and autonomy; social policy, citizenship and advocacy; clinical governance; social interface; human rights; and recovery-based practice. The international panel comprised members with expertise on: rehabilitation and recovery; using services and representing other service users; international mental health law; human rights law; disability rights; and care quality standards. A draft toolkit was drawn up by the consortium and the international expert panel comprising 154 questions that assessed these nine domains.

## **Testing the reliability of the toolkit**

The draft toolkit was piloted in each of the ten countries and inter-rater reliability testing was conducted in 20 units in each country. The units recruited provided high levels of support (24 hours) for at least a year to at least six people with longer term mental health problems living communally. Unit managers were interviewed twice and ratings compared statistically for reliability. Managers and researchers also completed feedback questionnaires regarding the toolkit's relevance, its potential usefulness as an internal auditing tool, the ease of access to relevant data to answer the questions, and the time taken to complete it.

## **Toolkit refinement**

The toolkit was refined in light of the results of reliability testing. Unreliable items were excluded, amended or kept as descriptive items. An exploratory factor analysis provided a statistical check of the original allocation of questions to domains used when developing the draft toolkit. Two domains (social policy, citizenship and advocacy; and clinical governance) did not appear robust when this process was completed. The toolkit was therefore reduced to seven domains (living environment; therapeutic environment; treatments and interventions; self management and autonomy; human rights; social interface; and recovery based practice). The final toolkit comprises 145 questions and can be completed within 60 minutes.

## **Cross-validation of toolkit scores against service user experiences**

The particular problems of those residing in longer term units mean that many lack capacity to give informed consent to participate in interviews about their quality of care. For this reason, the association between service users' experiences of care and managers' toolkit ratings were investigated to see if the toolkit was able to reflect not just the manager's views, but those of service users too. Unit managers were re-interviewed using the refined toolkit and at least five service users were assessed from each unit using standardised measures of quality of life, autonomy, experiences of care, functioning and the therapeutic culture of their unit. A total of 213 units and 1749 service users participated. Significant positive associations were found between all toolkit domains and service users' experiences of care and autonomy. These results allow future users of the toolkit to have confidence that the domain ratings derived from the unit manager's ratings reflect the service user experience. In situations where service user interviews are not feasible (e.g. due to resource limitations or where service users are unable to participate) the toolkit domain ratings given by the unit manager can provide a proxy assessment of the unit's promotion of its service users' autonomy and experience of its care.

## The Quality Indicator for Rehabilitative Care

The toolkit was named QuIRC and has been developed as a web-based self-assessment tool for completion by the unit manager. It uses a computerised algorithm to produce individualised, printed reports which detail unit performance in the seven domains of care. These are plotted on a radar chart and the results for similar units in their country are also shown for comparison. The report also gives further details about the results and the areas of care the unit could focus on to improve their results. The web based version of QuIRC has been translated into ten languages and can be found at: <http://www.quirc.eu>



## Use of QuIRC as a quality benchmark and a research tool

QuIRC has been incorporated into the UK's peer accreditation process for inpatient mental health rehabilitation units ("AIMS-Rehab") co-ordinated by the Royal College of Psychiatrists' Centre for Quality Improvement. The AIMS programmes are unofficially endorsed by the Care Quality Commission, the UK's independent body that inspects and registers health and social care facilities. The Czech Psychiatric Association also plans to promote the use of QuIRC as a national quality assessment tool for rehabilitation units and a leading centre for mental health rehabilitation in the Netherlands also plans to promote it. In Portugal, Greece, Bulgaria and other countries that participated in the DEMoBinc project, the incorporation of QuIRC into routine quality assessment processes for longer term units is under discussion with relevant parties. The EC has suggested that the QuIRC may be useful as a pan-European quality benchmark.

The use of QuIRC across countries will lead to the accumulation of international data on the quality of care in longer term mental health units. These data will be of use in monitoring quality of care across Europe and in assessing the impact of interventions to improve quality. The QuIRC has already been incorporated into a national study of inpatient rehabilitation services in the UK led by Helen Killaspy (Rehabilitation Effectiveness for Activities for Life). Similar studies are being developed in Portugal and Spain.

## Publications

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Invited paper for the thematic conference:

## **Empowerment in Mental Health –**

# **A partnership project of the WHO Regional Office for Europe and the European Commission**

## **Fact sheet for the EU Thematic Conference “Promoting Social Inclusion and Combating Stigma for Mental Health”**

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### **Why empower people with mental health problems?**

People with mental health problems and their families have not been involved as equal partners in decision-making processes on mental health services, and they continue to be at risk of social exclusion and discrimination in all facets of life. In a mental health context, empowerment refers to the level of choice, influence and control that users of mental health services can exercise over events in their lives, and the key to empowerment is the removal of formal or informal barriers and the transformation of power relations between individuals, communities, services and governments (WHO 2010a).

Despite all achievements that have been made over the past decade, there is still a strong need for empowerment of people with mental health problems and family carers. The WHO report on “Policies and practices for mental health in Europe – meeting the challenges (WHO 2009) shows that users are represented on committees responsible for planning mental health services in less than half (49%) of the 42 countries of the European Region which participated in the survey; even fewer countries (15 of 42) indicated that service users are represented on committees responsible for implementing policy on mental health services. Representation of service users and carers on inspection visits to mental health facilities, a commitment in the Mental Health Declaration for Europe (WHO 2005), is far from standard in every part of the WHO European Region. The involvement of family carers in planning, implementing and monitoring mental health services is similar to that of service users.

In the light of this background, the World Health Organization Regional Office for Europe and the European Commission started a three years lasting “Partnership Project on Empowerment in Mental Health” in 2008 which aims to support Member States in the European Region in creating societies in which people with mental health problems are enabled to develop and express their full potential as equal citizens.

## **Empowerment in European and global policy framework**

Empowerment has been recognized as a core element of health promotion and disorder prevention in various international instruments such as the Ottawa Charter on Health Promotion (WHO 1986) and the Bangkok Charter for Health Promotion in a Globalized World (WHO 2005). The more recent European Strategy for the Prevention and Control of Non-communicable Diseases says that “People should be empowered to promote their own health, interact effectively with health services and be active partners in managing diseases” (2006:1).

More specifically, the empowerment of people with mental health problems and those who care for them are identified as key priorities for the next decade in the Mental Health Declaration for Europe (WHO 2005). At the Ministerial Conference in Helsinki in 2005, the Ministers of Health of the Member States of the WHO European Region committed themselves to enforce mental health policy and legislation that sets standards for mental health activities and upholds human rights, to eliminate stigma and discrimination and empowering people at risk, and to offer people with mental health problems choice and involvement in their own care.

The participants in the EU high-level conference *Together for Mental Health and Well-being* in Brussels in June 2008 acknowledged with the European Pact for Mental Health and Well-being (EC 2008) the importance and relevance of mental health and well-being for the European Union, its Member States, stakeholders and citizens. They expressed their recognition of mental health as a human right that enables citizens to enjoy well-being, quality of life and health that promotes learning, working and participation in society.

## **The WHO-EC Partnership Project on Empowerment in Mental Health – statement, indicators, and recommendations for action**

The main objective of the partnership project is to support Member States to improve their strategies and actions to empower mental health service users and their families. Partners from user and carer associations and other experts from policy, human rights, NGOs, mental health services and research form the advisory group to the project.

In spring 2009, a WHO Conference on “Mental Health and Wellbeing at the Workplace – Protection and Inclusion in Challenging Times” has been conducted, supported by the EC Directorate for Health and Consumers. A report on the conference theme has been published in October 2010 on occasion of World Mental Health Day. The report reflects the presentations at the Conference and suggests ways to respond to how modern working life challenges mental health and well-being, how to overcome barriers to employment for people with mental health problems and opportunities for integration and empowerment given the global economic downturn from the viewpoint of user and family caregiver associations, enterprises, trade unions, politicians and researchers (WHO 2010b).

The advisory group to the project developed the “WHO Statement on Empowerment in Mental Health” which was published in early 2010 (WHO 2010a). The statement defines empowerment, identifies its multi-dimensional aspects from the viewpoint of users, carers, human rights experts, researchers, service providers and experts from other relevant areas. The statement proposes action at the societal level, at the level of service development and provision, education and training of health professionals, users, carers and the community.

On the basis of the WHO Statement on Empowerment in Mental Health and its recommendations for action, 19 indicators for user and carer empowerment in mental health, applicable at national level, have been identified in the following areas:

- Protection of human rights;
- Inclusion in decision-making;
- High-quality care and accountability of services;
- Access to information and resources.

A complete list of the indicators is provided below.

Another achievement of the project is a collection of about 100 practice examples from across the European Region. The practices range from the implementation of local self-help groups to regional cultural events that aim at de-stigmatization of mental health problems to skills trainings for family carers. Most of the initiatives are lead by users and carers.

A number of these practice examples were presented at the WHO Meeting on Empowerment in Mental Health – Working towards Leadership in Leuven, Belgium, on 27-28 Oct 2010. The purpose of the meeting was to bring together local and national champions of empowerment and government representatives to discuss concrete opportunities for user and carer empowerment. More than 100 participants from across Europe discussed the role of governments, communities and services as well as the opportunities and challenges for mental health service users to become leaders and to create change. As background information for the meeting 6 briefing papers on different aspects of user and carer leadership in empowerment have been produced. The topics of the briefing papers are:

- Self-management of mental health problems (Crepaz-Keay 2010)
- Mental health service user leadership in research (Callard & Rose 2010)
- User empowerment: implications for training the mental health workforce (Greacen 2010)
- Employability interventions for people with mental health problems (Bacon & Grove 2010)
- Quality assurance/monitoring of mental health services by service users and carers (Sweeney & Wallcraft 2010)
- Family carer education in mental health (Jones 2010).

A WHO Regional Office for Europe report on “Empowerment in Mental Health” will be produced in 2011 in order to ensure the mainstreaming of the knowledge and practice collated within this project.

## **Indicators for empowerment of mental health service users and family carers**

In the framework of the WHO-EC partnership project the following 19 indicators have been identified:

### ***Protection of Human Rights***

1. People using mental health services\* have the right to vote.
2. People using mental health services\* have the right to hold public office.
3. The country has employment legislation that forbids discrimination in employment on the basis of diagnosis or history of mental illness.
4. The country has employment legislation to cover the needs of family carers.

\* People who either in the past have used or are presently using mental health services.

### ***Inclusion in decision-making***

5. Mental health service users and their families are involved in the development of mental health policy and legislation.
6. Mental health service users and their families have authority in the process of designing, planning and implementing mental health services.

### ***High-quality care and accountability of services***

7. People with mental health problems and their families have access to appropriate mental health services.
8. People with mental health problems have access to general health services like other citizens.
9. People with mental health problems have the opportunity to be actively involved in the planning and review of their own care.
10. Families of people with mental health problems have the opportunity to be actively involved in the planning and review of care.
11. Mental health service users and their families are involved in inspection and monitoring of mental health services.
12. People with mental health problems and their families are involved in education and training of staff working in mental health services.

### ***Access to information and resources***

13. Mental health service users have a right to access their medical records.
14. People subjected to formal interventions due to their mental health problems have access to affordable legal support.
15. People with a disability caused by a mental health problem and their families have equitable access to state benefits.
16. Public funds are available for national user and family organizations.
17. Accessible and appropriate information and education about services and treatment is available for people with mental health problems.
18. Adequate information and education is available for families of people with mental health problems to support them in their role as family carers.
19. The welfare benefit system compensates for the financial implications of being a family carer.

### **Recommendations for action**

In order to achieve empowerment of people with mental health problems and family carers it is necessary to transform the distribution of power and resources including equal distribution of collective power and empowerment of individuals and groups. This implies that people with mental health problems have the power to set the agenda, make decisions and control resources, and unless the individual, service and societal levels are aligned, empowerment initiatives will not be effective and stigma, discrimination and marginalization will endure. Thus, empowerment needs to take place simultaneously on the individual and the societal level, forces need to be joined and action needs to be taken at various levels to strengthen leadership of users and family carers in empowerment.

#### ***At the political/societal level empowering users and carers means:***

- Ensuring that the full range of people service users' rights is respected, protected and fulfilled. That means for example that governments implement existing human rights instruments many of which cover people with mental health problems either specifically or by implication;

- Establishing funding and other mechanisms to support service user involvement and leadership, also in research. This includes opportunities for appropriate training and development, mentoring, career pathways and capacity building;
- Ensuring government activities to reduce stigma and discrimination and to conduct mental health promotion and disorder prevention programmes at national level and in communities;
- Conducting programmes which promote mental health in the workplace and work to reduce stigma, discrimination and bullying;
- Developing policies that ensure that families are recognized and not taken for granted and that their role can be demonstrated to be valued, for example through involvement of family representatives in the development of mental health policy making.

***At the level of service provision and development empowering users and carers means:***

- Making sure that people with mental health problems and their families have access to appropriate mental health services;
- Ensuring that people with mental health problems have access to general health services like other citizens;
- Involving users and carers as equal partners at all stages of running, planning, delivering and evaluating services;
- Ensuring that independent review bodies with users and carers on board are in place to review treatment and services;
- Actively involving families in the design, planning and implementation of mental health services.

***At the level of education and training:***

- Making sure that accessible and appropriate information and education about services and treatment is available for people with mental health problems and for their families;
- Designing and delivering mental health professionals' training in systematic partnership with users and families;
- Including the stigma of mental illness as a topic in the curricula of primary care and mental health professionals;
- Offering trainings also for relevant community actors such as employers and police officers.

The WHO Regional Office for Europe, in partnership with the European Commission, and strongly supported by the advisory group to the partnership project, has developed this initiative to support Member States in developing and implementing policies, strategies and activities to empower people with mental health problems and their family carers and has identified indicators to steer this process. The recommended actions must now be taken forward by all involved stakeholders; initiatives embracing empowerment and social inclusion will not only offer opportunities and equality to the most vulnerable and discriminated groups, but will benefit communities as a whole.

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## Best Practice in Health Services for Immigrants in Europe - EUGATE

EUGATE aims to identify best practice of health care delivery to migrants and therefore focuses on migrants who already are in contact with health services. The project reviewed existing legislation and policies, obtained the opinions of experts on factors constituting best practice, and assessed the views of practitioners in different types of health services. The study was conducted in 16 EU countries: Austria, Belgium, Denmark, Finland, France, Italy, Lithuania, Germany, Greece, Hungary, Netherlands, Poland, Portugal, Spain, Sweden and the United Kingdom. Here we summarise the findings of a Delphi process on best practice and of interviews with practitioners.

### Interviews with practitioners in health services

In each participating country we identified three urban areas with relatively high levels of immigrants. In each area we selected a) an Accident and Emergency (A&E) Department in a general hospital; b) a service providing long-term care for patients with chronic and severe mental illness; and c) three primary care services (e.g. GP practices), and interviewed a practitioner. In total we conducted face-to-face interviews with practitioners in 240 services (primary care=144, mental health care =48, A&E=48). The interview consisted of three components: a) general information about service use, evaluation and monitoring mechanisms; b) questions on general experiences; and c) questions on how practitioners would deal with patients as represented in three case vignettes (undocumented immigrant, refugee and labour immigrant). All interviews were subjected to content analysis using a jointly developed and consistent coding scheme across all countries.

We identified eight problem areas and seven components of good practice to overcome these problems. The **eight problem areas** reported were:

- language barrier (e.g. patients were unable to provide relevant information, clinicians struggled to reach diagnoses and often felt compelled to arrange additional examinations and diagnostic tests; communication problems also led to misunderstandings between staff and patients leading to a strained relationship, verbal aggression or even physical violence);
- different cultural norms and specific diseases (e.g. culturally specific health problems and communication problems, dress code, attitude to nudity, dietary requirements, gender roles);
- specific stressors for immigrants (e.g. lower socioeconomic status, legal status issues, pre-migration trauma and migration related stress and mental health);
- different understanding of illness and treatment e.g. cultural difference in perception and expression of illness and treatment which may act as barriers in reaching appropriate diagnoses and may affect treatment choice and adherence);
- lack of knowledge of health care system (e.g. not understanding the practitioner's role, differences in treatment expectations);
- negative attitudes among staff and patients (e.g. consequences of negative attitudes, such as discrimination and lack of trust);
- lack of access to medical history (including medical history being written in a language not understandable to the practitioner); and
- difficulties in arranging care for immigrants without health care coverage.

The **seven components of good practice** to overcome these problems were:

- good interpreting services (including same language therapist, bi-cultural workers as interpreters, professional interpreting services);

- cultural awareness of staff (e.g. promotion of cultural awareness through education or training of staff, having multi-cultural staff supports the wider acquisition of an understanding of different cultures);
- organisational flexibility with sufficient time and resources (including provision of culturally sensitive treatment and services, longer consultation time and better recourses);
- more focus on social issues and involving the family and close collaboration with social services (including collaboration with religious, community and refugee groups);
- education programmes and information material for immigrants (e.g. education programmes or translated material on health and health care system);
- friendly relationship with staff and continuity of care (e.g. permanency/familiarity of staff helps improve staff-patient relationship); and
- clear guidelines on care entitlements of different groups of immigrants (e.g. service policy, training of staff in immigrants entitlements).

### **Delphi process of expert opinion on what constitutes best health care for migrants**

In each participating country, experts from academia, NGOs, policy making and health care practice participated in a four step Delphi process to find a consensus on components of best health care for immigrants (in total 113 experts completed the process). The process focused on immigrants who a) had arrived within the last five years, b) were between 18-65 years of age, c) had a regular income, and d) did not originate from a developed country with a similar language. In each country between 10 and 16 most important components were identified.

The most frequent ones (mentioned by more than 50% of countries) fell into eight categories:

- access to health care;
- empowerment of migrants (in terms of their health and health determinants);
- cultural sensitive health services;
- general quality of health care;
- patient-health care provider communication (provision of interpreting and translation);
- respect towards immigrants;
- networking in and outside health services; and
- knowledge about specificities in migrant health care.

### **Conclusions about best practice**

Both parts together suggest the following characteristics of best health care for immigrants:

Good quality and easily accessible interpreting services

- Culturally sensitive treatment and services, including accommodating patient choice where possible (e.g. same-sex practitioner)
- Presence of staff from a range of ethnic backgrounds
- Promotion of cultural awareness through education and training education
- Education programmes and translated materials for immigrants on health and health care system
- An integrative approach with a close collaboration of health and social services
- Clear information and guidelines for services about what services different groups of immigrants are entitled to

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## **Best Practice In Promoting Mental Health In Socially Marginalized People In Europe - PROMO**

PROMO aims to identify best practice in promoting mental health and delivering care amongst socially marginalised groups. The focus is on the delivery of health and social care for people with mental health problems who belong to one of the six following groups: (1) long-term unemployed; (2) homeless; (3) street sex workers; (4) asylum seekers/refugees; (5) undocumented migrants; (6) travelling communities. The project was conducted in 14 countries: Austria, Belgium, Czech Republic, France, Italy, Germany, Hungary, Ireland, Netherlands, Poland, Portugal, Spain, Sweden, and United Kingdom. Here we summarise the findings of two main parts of the project: interviews with services providing care for these groups and interviews with experts about the quality of care provided for each group. All these interviews were conducted in the two most deprived areas in the capital of each country.

### **Assessment of services**

We identified services providing health and social care for any of the six marginalised groups in the two areas, and interviewed a representative from the services about providers and funding, characteristics of staff, accessibility, characteristics of clients, programmes provided, coordination with other services, and evaluation. In total, 617 services were assessed which were categorised into six groups: group specific mental health services (A1, n=51); generic mental health services (A2, n=221); group specific social care services (B1, n=84); generic social care services (B2, n=187); group specific physical (general) health services (C1, n=29); and generic physical (general) health (C2, n=45). They were additionally categorised according to target group within the group-specific services (A1, B1, and C1). Group specific services existed mainly for homeless populations (n=111), refugees or asylum seekers (n=58) or long term unemployed (n=45). Out of all assessed services, 49 were named as best practice models by other local experts. These services were specifically analysed.

Using an iterative process involving all partners we developed a Quality Index of Service Organisation reflecting the accessibility of the service, the extent of supervision arrangements, the multidisciplinary expertise of the staff, the programmes provided, the coordination with other services, and the evaluation of the service. Whilst the score varied substantially across services, overall services providing more diverse programmes of care and treatment were found to have a higher score.

### **Expert interviews**

In total, interviews with 154 health and social care experts were conducted. They contained questions related to two case vignettes (on pathways into mental health care, barriers encountered and ways to overcome them) and general questions on the coordination, strengths, and weaknesses of the care system as a whole for each of the six marginalised groups and the most important issues for improvement.

### **Barriers to mental health promotion and care**

Six types of barriers were found to be most important across all groups and countries:

- Limited entitlements to health care (or no coverage of costs) of marginalised groups, particularly of asylum seekers and undocumented migrants.
- Complex needs and limited ability to engage, because marginalised people often live in poor socio-economic circumstances, inadequate housing, and social isolation, having chaotic life styles and lack information on health services.

- Barriers linked to language and culture with a shortage of resources for trained interpreters (and a reluctance to use them where available) and often very different explanatory models for mental health problems.
- The organisation of services can contribute to further barriers when they are rigid in their administration and approach, especially if they fail to provide non-intrusive mental health outreach in the community and are poorly co-ordinated.
- Negative attitudes in health services towards some of the marginalised groups can lead to substandard treatment or rejection of clients, which is particularly relevant in the case of travelling communities, street sex workers and the homeless.
- Lack of trust in and even fear of health professionals, which may be associated with previous negative experiences with services (sometimes made in other countries).

### **General recommendations to improve practice**

The preliminary analysis of the different components of the collected evidence suggests five recommendations to improve practice across all marginalised groups and some specific recommendations for the each group. The general recommendations are:

- Develop flexible, non-intrusive outreach programmes in group-specific, but general health services that can address a range of health problems building up trust with marginalised people
- Provide a wider range of specific treatments in generic mental health services so that these services can use different approaches to care and avoid complicated referral procedures to other services for other treatment programmes
- Increase the availability of psychological treatments and of programmes to help people into regular employment such as job coaching
- Increase the collaboration and co-ordination of services on a local level, which might be achieved by as little as annual meetings of all services providing care for the same group in the same area
- Provide information on marginalised groups for services and on the available services for the marginalised groups both of which have to be appropriate and easily accessible

Specific recommendations to improve care for the studied marginalised groups are:

- **Homeless:** There should be a stronger focus on non-intrusive outreach and mental health competency within services that work with homeless people.
- **Long-term unemployed:** Practice varies enormously for this group, and there is no specific recommendation beyond the general ones.
- **Street sex workers:** There should be a stronger emphasis on the provision of mental health and addiction programmes.
- **Asylum seekers/refuges:** Non-intrusive outreach programmes with a particular focus on the provision of information to individuals and easy access to language support or interpreters.
- **Undocumented migrants:** More clarity (for both migrants and services) about their entitlements and the possibilities to treat with or without funding.
- **Travelling communities:** There should be a particular focus on personal contact with outreach services as a means of building trust and providing information before facilitating access to other services.

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