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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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Dr Anja Esther Baumann
Technical Officer, Mental Health Promotion & Disorder Prevention
Division of Non-communicable Diseases & Health Promotion
World Health Organization Regional Office for Europe
Scherfigsvej 8, DK-2100 Copenhagen, Denmark
Phone: +45 39 17 14 54
Email: anj@euro.who.int

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