Empowerment in Mental Health – Working together towards Leadership

27-28 October 2010, Leuven, Belgium

A meeting in partnership with the European Commission

WHO Regional Office for Europe
Editors
Dr. Anja Esther Baumann, Technical Officer for Mental Health
Dr. Matt Muijen, Regional Adviser for Mental Health

Acknowledgement
We would like to thank all conference participants, speakers, authors of background materials and the advisory group to the WHO-EC Project on Empowerment in Mental Health for their valuable input to the conference. Their participation and extraordinary commitment and engagement in empowering people with mental health problems and their families made this conference a unique and successful event.

We especially acknowledge the contribution of the rapporteurs Else Tambuyzer, Evelien Demaerschalk, Dr. Nele Spruytte and Prof. Dr. Chantal Van Audenhove from LUCAS – K.U. Leuven, Centre for Care Research and Consultancy, Belgium, who provided an excellent draft of this report.
Abstract

This WHO meeting took place in the framework of the WHO-EC Partnership Project on Empowerment in Mental Health. Mental health service users, family carers, service providers, human rights experts and policy-makers assembled and reflected on how to make empowerment in mental health a reality. Attention was given to the history of mental health care as well as to the growing interest and awareness for this subject in international health policy. Different components of the concept of empowerment were discussed, in particular how user and carer leadership can be strengthened. The conference addressed how empowering communities can be created, how services can be empowering and how health professionals’ training and education as well as employment opportunities for people with mental health problems can be improved. The promotion of human rights for mental health service users and the roles of governments in boosting change were considered. The WHO empowerment indicators were endorsed, and it is hoped that they will become levers of change and that their adoption at country level will stimulate implementation of good practice.
Introduction

Without genuine representation, no power, no change

Matt Muijen

Empowerment benefits everyone: the individual and the society

Catherine Gonzi

The ‘Empowerment in Mental Health’ meeting was convened by the WHO Regional Office for Europe in partnership with the European Commission Directorate for Health and Consumers. The meeting was hosted by EUFAMI, the European Federation of Families of People with Mental Illness and took place in Leuven, Belgium.

The WHO Empowerment Meeting in Leuven brought together government representatives and other relevant stakeholder as well as national and local champions to jointly take action in creating an environment in which people with the experience of mental health problems can live their full potential as citizens with equal opportunities.

The meeting was opened by Matt Muijen (World Health Organization Regional Office for Europe); Louis Tobback (Mayor of Leuven), Jürgen Scheftlein (European Commission DG SANCO), Debra Shulkes (European Network of (ex-) Users and Survivors of Psychiatry – ENUSP) and Kevin Jones (EUFAMI), followed by a Mrs Catherine Gonzi, the Patron of the WHO-EC Partnership Project on Empowerment in Mental Health. Each stressed the importance of this first meeting on empowerment in mental health, since it has the opportunity to put empowerment of service users and their families on the political agenda.

The meeting was attended by a diverse group of participants from 25 European countries (Albania, Belgium, Czech Republic, Denmark, Finland, France, Georgia, Germany, Greece, Iceland, Ireland, Italy, Lithuania, Luxembourg, Malta, Norway, Poland, Portugal, Slovak Republic, Slovenia,
Spain, Sweden, Switzerland, The Netherlands, and The United Kingdom) who represented a variety of organizations: user associations, family associations, governmental departments and ministries, psychiatric centres, hospitals and mental health care providers, WHO Collaborating Centres, pharmaceutical industry, universities and research institutes, diverse NGOs, human rights organizations, health management & health promotion associations, psychosocial rehabilitation services, and representatives from the organizing agencies.

Historically, people with mental health problems have lacked a voice and have been marginalised, as symbolised by the asylums. Neither they nor their families were involved in decision-making that affected their lives, whether in mental health services or in broader society, and they continue to be at risk of social exclusion and discrimination. However, the tide is changing steadily. During the past decade, the commitment to create opportunities for inclusion for this vulnerable group has been on the agenda of policy makers worldwide. The WHO Regional Office for Europe and the European Commission (EC) formulated the need for action in the Helsinki Declaration (WHO 2005) and the European Pact for Mental Health (EC 2008) and made empowerment of service users and their carers one of their key priorities.

The WHO Regional Office for Europe and the European Commission launched ‘The WHO-EC Partnership Project on User Empowerment in Mental Health’ in 2008. The project aims to support Member States in improving their strategies and actions towards empowering users and carers in mental health. The Partnership Project consists of four components:

1. Supporting governments and local actors in creating an environment for user and care participation;
2. Identification of indicators of user empowerment in mental health;
3. Collection of good practices in user empowerment;
4. Promoting the mainstreaming of good practice in user empowerment in mental health.

In the framework of the project a variety of actions have already been undertaken, such as the organization of a WHO Conference on Mental Health and Wellbeing at the Workplace – ‘Protection and Inclusion in Challenging Times’ in Berlin in 2009 and a WHO report on this conference, published in October 2010 (WHO 2010a). The WHO Statement of Empowerment in Mental Health was launched in early 2010 (WHO 2010b). Relevant indicators for empowerment applicable at national level have been developed and about 100 examples of practice have been collated.
Specifically for this meeting, six briefing papers were developed. The briefing papers present the following topics:

- User self-management;
- User leadership in research;
- Family carer education;
- Quality assurance and monitoring of mental health services;
- Training of mental health workforce;
- Employment opportunities for people with mental health problems.

This report provides an overview of the topics and outcomes of the meeting. A brief introduction into the theme of empowerment in mental health is provided in the context of the evolution mental health care has experienced during the recent decades. Subsequently, there are sections on empowering users and carers; developing communities that empower users and carers, and working with governments towards empowerment.
The evolution of mental health care

The voices of service users and their carers have been getting louder during the last decade, although the onset, speed and pervasiveness of their involvement has varied greatly from country to country. With the deinstitutionalisation of mental health care and the introduction of community based services, the mental health field has experiences comprehensive conceptual changes. Table 1 provides an overview of some of the most striking of these changes.

Table 1  The evolution of mental health care.

<table>
<thead>
<tr>
<th>Changes in...</th>
<th>from...</th>
<th>to...</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health care</strong></td>
<td>Institutions/asylums</td>
<td>Community care</td>
</tr>
<tr>
<td></td>
<td>Hospitals</td>
<td>Circles of support</td>
</tr>
<tr>
<td></td>
<td>Paternalism, hierarchy</td>
<td>Horizontal approach, equal partnerships</td>
</tr>
<tr>
<td></td>
<td>Cure</td>
<td>Recovery</td>
</tr>
<tr>
<td></td>
<td>Treating the disease</td>
<td>Promoting and maintaining life skills</td>
</tr>
<tr>
<td></td>
<td>Coercion</td>
<td>Cooperation</td>
</tr>
<tr>
<td><strong>Focus</strong></td>
<td>Biomedical model</td>
<td>Holistic/bio-psychosocial model</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>Self-determination and autonomy</td>
</tr>
<tr>
<td><strong>Professional</strong></td>
<td>Caregiver</td>
<td>Enabler</td>
</tr>
<tr>
<td><strong>Service user(^1)</strong></td>
<td>The ‘mad’ patient</td>
<td>Service user, citizen</td>
</tr>
<tr>
<td></td>
<td>As an object</td>
<td>As a subject</td>
</tr>
<tr>
<td></td>
<td>Defined in terms of deficits</td>
<td>Defined in terms of possibilities</td>
</tr>
<tr>
<td><strong>Carer</strong></td>
<td>Excluded from their family member’s care</td>
<td>Becoming a partner in care</td>
</tr>
</tbody>
</table>
The perception of the role of service users has changed thoroughly. A few decades ago, they were seen as patients who lack an understanding of what is good for them. Currently, they are becoming more and more involved in their own treatment and recovery. Their voices have not only been strengthened at this individual level, but also at the group level. Service users as well as family members have been assembling in associations. In these movements, people do not solely gather and share experiences, but they also advocate for their members’ rights and strive to be involved in health care policy.

Empowerment of service users and carers is one of the priorities of the Helsinki Declaration (WHO 2005) and the European Pact for Mental Health (European Commission 2008). A central element of empowerment is participation. Various international instruments recognize the essential role of participation in realizing fundamental human rights, such as the UN Convention on the Rights of Persons with Disabilities with its explicit social development dimension. The UN Committee on Economic, Social and Cultural Rights, in its 2000 General Comment No 14, The Right to the Highest Attainable Standard of Health, provides that participation of the population in all health-related decision-making at the community, national and international levels is an important aspect to the right to health. Article 4 of the Alma-Ata Declaration on Primary Health Care states that “people have the right and duty to participate individually and collectively in the planning and implementation of their health care”. Empowerment has been recognized as a core element of health promotion and disorder prevention as stated in the Ottawa Charter on Health Promotion and the Bangkok Charter for Health Promotion in a Globalized World, and the more recent European Strategy for the Prevention and Control of Non-communicable Diseases indicates that “People should be empowered to promote their own health, interact effectively with health services and be active partners in managing diseases”.

Table 2 provides an overview of relevant worldwide and European policy documents in international policy stressing the importance of participation and empowerment.

<table>
<thead>
<tr>
<th>Year</th>
<th>Policy Document</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>1978</td>
<td>The Declaration of Alma-Ata</td>
<td>People have the right and duty to participate individually and collectively in the planning and implementation of their health care.</td>
</tr>
<tr>
<td>1986</td>
<td>Ottawa Charter for Health Promotion</td>
<td></td>
</tr>
</tbody>
</table>
We need to advocate, enable and mediate the encouragement of health promotion.

<table>
<thead>
<tr>
<th>Year</th>
<th>Document Title</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>The Right to the Highest Attainable Standard of Health</td>
<td>We need affective and integrated health systems that are transparent.</td>
</tr>
<tr>
<td>2004</td>
<td>European Strategy for the Prevention and Control of Non-communicable Diseases</td>
<td>People should be empowered to promote their own health.</td>
</tr>
<tr>
<td>2005</td>
<td>The Bangkok Charter for Health Promotion in a Globalized World</td>
<td>Health promotion needs to be on the global development agenda and we need to determine responsibilities for the local governments.</td>
</tr>
<tr>
<td></td>
<td><strong>Mental Health Declaration and Action Plan for Europe</strong></td>
<td>We need to foster awareness on the importance of mental wellbeing, tackle stigma and empower service users, carers and nongovernmental organizations.</td>
</tr>
<tr>
<td></td>
<td><strong>Helsinki Declaration</strong></td>
<td>We need to set standards for mental health activities, eliminate stigma and offer people with mental health problems choice and involvement in their own care.</td>
</tr>
<tr>
<td>2007</td>
<td>European Pact for Mental Health and Wellbeing</td>
<td>Empowerment of people with mental health problems and those who care for them are key priorities for the next decade.</td>
</tr>
<tr>
<td></td>
<td><strong>The UN Convention on the Rights of People with Disabilities</strong></td>
<td>People with disabilities are subjects with rights, who are capable of claiming those rights and making decisions for their lives.</td>
</tr>
<tr>
<td>2008</td>
<td>European Strategy for the Prevention and Control of Non-communicable Diseases</td>
<td>People should be empowered to promote their own health.</td>
</tr>
<tr>
<td>2010</td>
<td><strong>WHO statement on user empowerment in mental health</strong></td>
<td>The key to empowerment is to remove formal and informal barriers and to transform the power relations between individuals, services and governments.</td>
</tr>
</tbody>
</table>
Empowering mental health service users and carers

The concept of empowerment

In order to understand each other and to make user empowerment a reality, it is necessary to be explicit about the meaning of empowerment and gain a common understanding of the used definitions. During the meeting, several descriptions and definitions of the empowerment concept were highlighted. Many speakers and participants of the meeting referred to the following statement on user empowerment in mental health (Wallerstein 2006):

“Empowerment refers to the level of choice, influence and control that users of mental health services can exercise over events in their lives. The key to empowerment is the removal of formal or informal barriers and (...) the transformation of power relations between individuals, communities, services and governments.”

Empowerment is thought to be a transformative process, thus an ongoing process more than just a state. It is also an overarching concept and can be associated with several other aspects of care, such as deinstitutionalisation, information, support, meeting basic needs, involvement, service & staff development and self-determination & self-management.

Two challenges need to be borne in mind while considering empowerment and empowering users and carers:

Not seeing everyone as a homogenous group (everyone has different aspirations)

It’s important to keep the diversity of the target groups in sight as empowerment can mean different things to different people. For some, being empowered may be about access to services, while for others it may signify choice of services or the right to decline services. Despite all these differences, some delegates stressed that the experiences of exclusion, stigma and discrimination can be very similar among the different groups.

Not every service user has the same needs
The group of service users is very diverse. The nature of their illness will ask for tailored approaches. Indeed, the experience of the approximately 3% of service users with a ‘severe’ mental illness is not the same as that of the rest of the service users with more ‘mild’ mental health problems. Furthermore, the characteristics of individual service users (e.g. age, gender, culture) and their context are to be taken into account.

*Users and carers don’t have the same needs*

There are reasons why users and carers should be distinguished. Both groups often experience stigmatization in a different way, leading to different opinions and interests and different agendas. This was strikingly called “the elephant in the room”, pointing out to the different needs that are so obvious but that have been ignored and unaddressed for a long time. However, it is a step forward that these differences are now recognized. For some service users it was a concern that their family would obtain a special status, equal to the power status of health care professionals.

*User movements do not necessarily share the same opinion*

The concerns and actions of user movements and representations may differ in various aspects. They can differ in their starting point, namely the human rights perspective opposed to a consumerist perspective. But they can also be focused at individual service users or at the collective (the group). Lastly, user movements can take a separatist or a collaborative view to health care providers. These differences can have far reaching consequences and are often mirrored in the language used by the movements.

*Seeing that everyone can be affected by mental health problems (communalities).*

Some participants and speakers questioned the application of the term ‘user’, claiming that the term focuses on the differences instead of on the communalities with the rest of the population. Every single person has a chance of experiencing mental health problems throughout the lifespan, and when looking at the prevalence of mental health problems, this experience is not rare. However, since some people have come to identify themselves as someone who has had that experience, the use of a term might be useful, although “the word user is imperfect”.

*Components of empowerment*
In order to create an environment that empowers people, it needs to be assured that all core conditions of empowerment are met. The following section presents the key points of the presentations and discussions by means of the subcomponents of empowerment as defined in the WHO Statement on User Empowerment in Mental Health (WHO 2010): transformation of power relations, participation in decisions, dignity and respect and belonging and contributing to a wide society and self-reliance (Figure 1).
Figure 1  Subcomponents and related concepts of empowerment.
Power

Historically, segregation and coercion (being locked up, forced treatment, abuse, and neglect) have been examples of a large power imbalance between health care professionals and service users. As the word says, power is a central aspect of empowerment. The question is about how to give a voice to those who cannot speak for themselves, without “making them want what you want them to want”. Peer support can be a way to give them a voice. Another key source of power is access to resources although “It’s not just about resources; it often requires more thought than money”. In relation to power, tokenism is a well-known risk: overtly, service users and carers are involved, but in reality they have no power.

Participation in decisions
To be able to participate in decision making, people need access to information. This is the case for service users, carers, professionals and for people in the wider community. The difference lays in the kind of information the different groups request and require. For example, users may want information about research into the causes, treatments and possible reactions to therapies, medication, etc. so they can become a knowledgeable partner in care related decision-making. Yet, the information alone won’t be sufficient but needs to be conveyed through effective communication.
Dignity and respect
The attitude and tolerance of professionals towards service users and carers are crucial. Their views and beliefs can have a large influence on wellbeing of users and carers, including diagnosis, treatment and provision of community resources. A respectful attitude can be empowering in itself. As Clemens Huitink pointed out in his presentation, respect means the following:

Responsive Encouraging Sensitive Perceptive Empowering Caring Thoughtful

A number of professional competencies were said to promote dignity and respect: the ability to listen, the use of own life experiences, an optimistic view and the willingness to take positive risks. In showing dignity and respect, the language used is important as well. Jargon can be a major barrier for users and their representatives when becoming involved in health care policy. Another aspect of respect is valuing user-created knowledge, as users are experts by their own experience.

Belonging & contributing to a wider society
Mental service users and family members are part of many groups and entities. The quantity and quality of someone’s social relations influences both well being and morbidity and mortality. It is therefore necessary to look at a person in a holistic way, see a person also as a part of her and his social environment.

Self-reliance
Empowerment is also about self-determination, autonomy and the power to make decisions. It is about sovereignty, free choice and about the transfer of control back to individuals. A good start for people to become self-reliant is the creation of equal partnerships between service users and providers. To concentrate on people’s lives and recovery and improving quality of life rather than focussing on illness and curing is the starting point. Self-management is a good practice example of how service users can control their own treatment and lives. An example of users and families taking control themselves are the self-help groups where people can exchange information and experiences about what they go through and how they can cope.

We can’t be empowered, we can only empower ourselves
Developing communities that empower users and carers

When talking about empowerment of service users and their carers, the role of community support is crucial. It is the task of communities to lever in resources, negotiate with services and provide support so that citizenship is not put at risk, the more so now deinstitutionalisation of care increases this role. Empowerment at community level may:

- Improve citizen’s advocacy, participation and solidarity;
- Improve functioning at work, schools, and institutions.

At the meeting several examples were given how communities can be developed to empower users and carers. Ways of how to create empowering services involving experts by experience are presented in the following.

Creating empowering services

In many mental health care services, ‘democratization’ of health care delivery is the new buzz word, around which efforts are made to enhance empowerment of service users and carers.

Ideally, empowering services offer the following:

- A human approach (listening, caring, using own experience), promoting citizenship roles and empowerment;
- A comprehensive range of support; not only focussing on the clinical part; a large part of the workforce should be located outside the hospital;
- Services are well linked with local opportunities – enabling social inclusion;
- Explicit components of information, self-management and recovery;
- An optimistic approach, being able to take positive risks;
• Service users as partners in planning, implementation and evaluation – coproduction model, ‘being’ partners’, instead of ‘having’ partners; institutional relationships are changed into real relationships;
• Services do not hold on to people but equip them.

However, there is still resistance from services to realize the vision of empowering users and carers, and tokenism remains prevalent.

In creating empowering services, two issues arise:

1. Communities and professionals must learn to value expertise by experience;
2. The creation of a system which takes a whole system-approach to avoid the split of clinical services in the community on the one hand and other institutions for rehabilitation and social inclusion on the other hand.

Using service user and carer experience

Despite the above mentioned statements ‘not all the service users are the same’ and ‘we also need to focus on the commonalities between users and not-users’, we cannot ignore the self evident fact that users are the only ones who have the actual experience of being a mental health service user. Only they know what it feels like to experience a mental health problem and they know what it means to be confronted with all the subsequent consequences. Family members in turn know what it means to live with and care for their loved ones. This unique and specific knowledge and experience can be useful for different purposes.

In research

Service user research is becoming more and more prevalent and research projects undertaken by service users already had a powerful impact. Service user involvement in research can empower those actively involved as well as those not directly taking part. Although service user research is gaining momentum, service user researchers often face very rigid hierarchies in the research environment, for example in the university sector. Two main obstacles include scepticism and the denial of user-produced knowledge which leads to undermining users’ credibility as researchers. Frequently, the hierarchy of evidence is used in their disadvantage by classifying the expert opinion as the lowest form of evidence. Furthermore, users are charged with bias, taking no account of the fact that research is always coloured by the perspective of the researcher. Thus, this charge does not exclusively apply to service user research.
**In training**

Mental health service users and their family members can give valuable input to the training of health care professionals and other users and family members. More details can be found in the example of the PROSPECT project provided on the next page (paragraph 2.3.3).

**In policy**

Users also can offer policy makers valuable experience at local, national and European levels. More and more Member States strive to involve service users at government level. In this way, they can use their personal expertise by experience and change the system from within. Their role should be the same as the role of others working at the government: to serve and to work towards a common good. Difficulties they may encounter include being reduced to their diagnosis, tokenism and stigmatization and discrimination.

**Training and education for service users, family carers and health care professionals**

Training and education is needed for service users and family carers as well as for health care professionals, and lifelong learning needs to become a standard.

Good examples of effective, user-led training programmes are the EMILIA Training (www.entermentalhealth.net/EMILIA_2/Training/home.php) and the “In-sight training” (www.recoveryin-sight.com).

Most families of people with mental health problems are not adequately prepared for the increasing demands they face. To stand up to these demands, they not only need information about characteristics of illnesses and treatments, but they also need to be involved in the care of their family member. They may request partnerships and collaboration with health care professionals. Professionals not only need to involve family members for their role concerning the service user, but also because they have themselves an increased risk of mental health problems.

An effective programme for **carer education** is PROSPECT which aims to support families and to encourage autonomy for the person with mental illness by creating a favourable family environment. The module for family members takes the form of a reflection with 4 stages:

1. Recognition by peers;
2. Become aware of what we are going through;
3. How to face up to the situation (peer-to-peer training);
Dare to change.

In order to work in partnership with empowered users, health care professionals need training, not just concerning knowledge but also about values and attitudes. They need continuous education to learn to collaborate on equal footing with service users and carers. Most of the training packages for service users and carers also include tools for training of health care professionals.

**Improving employment opportunities**

Employment is an essential feature in most people’s life. Having a job is a very important determinant for our social identity. Therefore, maintaining or regaining a job after a period of absence is of utmost importance. It not only has an economic but also a personal and social value. This is not less the case for people who experienced a mental illness. However, discrimination in the access to and maintenance of employment of people with mental health problems is still a fact. Recent national actions like setting up quota for disabled employees or providing fiscal benefits for employers have increased awareness. Still, discrimination continues and people experience the burden of stigma. In many countries support is provided to help (ex-) users to find a job. The most common approach is to ‘train then place’, although it has been shown that the ‘place then train’ of Individual Placement and Support (IPS) produces better outcomes. The core characteristics of IPS are:

- Intensive support to...
- accessing competitive, paid employment...
- followed by time-unlimited in-work support...
- for both employer and employee.

For IPS to be successful certain preconditions need to be met and actions need to be taken, for example:

- Designing healthy workplaces;
- Changing the mindsets of employers and their employees;
- Promoting rehabilitation programmes through club houses (www.iccd.org);
- Promoting social firms run by users;
- Disseminating good practices.
Working with governments towards empowerment

What is the role of governments in realizing the vision of empowering societies? Does the government need to work top down? Or is it their role to sow seeds, stimulate grass root practices and assess outcomes, for example by setting standards?

Quality assurance

If we want to effect all the before mentioned actions to stimulate empowerment, we need to evaluate if and where the impact of the actions occurs. For this, we need to develop standards and rate outcomes by the use of indicators. The identification of these standards and indicators for user and carer empowerment in mental health is one of the components of the WHO-EC Empowerment Project. Their goal is to develop usable as well as useful indicators. For this, indicators need to be measurable, auditable, meaningful, transferable, objective effective at measuring change over time, practicable to implement and offer a scale for benchmarking and improvement. Indicators serve several purposes; they can be used to highlight good as well as bad practices; as a tool for discussion and negotiation; and to promote and measure concrete and sustainable actions that result in empowerment.

The WHO-EC Partnership Project developed 19 indicators which cover four main areas:

1. Protection of the human rights of service users and fighting stigma and discrimination;
2. Inclusion in decision-making;
3. Ensuring high quality care and accountability of services;
4. Having access to information and resources.

The indicators provide a tool for assessment at the national level. The members of the indicator development group recommend to Member States annual application of the indicators and to publish and disseminate the results of the assessment. This information will allow a determination of standards and measurement of progress. In this process, it is necessary for the indicators to be available and visible. They should not be disseminated available to user and carer associations, and all partners should be encouraged to promote them.

As in the development of the draft indicators, service users, carers and other stakeholders can contribute to the process of refining the indicators and in their monitoring. Their participation can range from participation in surveys to being partners in service inspection teams. The
benefits of taking part in monitoring are: developing better outcome indicators, improving the quality of the information, discovering practical change strategies and enhancing peoples' skills, confidence and sense of worth.

If what we are doing makes a difference, we should be able to measure the impact we are making

David Crepaz-Keay

Role of WHO

The role of the World Health Organization was repeatedly described as being a catalyst of change and facilitator of the process. WHO was requested to develop capacity building and “keep the ball rolling”. WHO can stimulate user leadership and remove the thresholds for it.

It was suggested that the WHO-EC Empowerment Project should be implemented in the field, and the indicators should be tested and validated in some countries. It was recommended to start this process in partnership with a national umbrella organization. It was also mentioned that the WHO should only develop general indicators concerning human rights and should not develop specific local indicators, which are bound to be culturally diverse. Rather, the WHO should disseminate procedures to develop good local indicators.

Role of governments

The role of governments should not be a top-down one. It should rather be to set frameworks for empowerment and service user and carer involvement. These frameworks set the standards, exemplify good practices centrally and reflect the approach taken by the government. Thus, the core role of the government can be thought of as:

• Setting the value framework;
• Setting the service framework and policy goals;
• Regulating services and professionals;
• Setting the expectations for involvement;
• Releasing resources;
• Preventing discrimination;
• Creating incentives.

Another task for governments, central and local, is to stimulate the design of workplaces. Usually, we think of adjusting workplaces in a very physical way. We should also think about what accessibility means in terms of mental ill health. Related to this, governments should ensure that the mental health workforce receives training regarding empowerment. This training should occur in partnership with users and carers. Apart from training opportunities for the workforce, service users and carers should also be offered the possibility to receive training regarding empowerment and involvement. An additional key task of governments is to support the development of IPS (Individual Placement and Support) to make paid and competitive job support possible for people who experienced a time out from work due to mental health reasons. Furthermore, governments should develop policies to ensure that the role of families is recognized and not taken for granted. Lastly, governments should implement international human rights laws.

Resources and funding

A lack of resources can result in several problems. Firstly, it can lead to a chronic underrepresentation of service users and/or carers. Secondly, the sustainability of organizations is put at risk. Systematic funding of user and carer organizations is essential, so that these groups can develop and be represented. A simple example is the reimbursement of travel costs. Financial support to service user and carer associations is thought to be a good investment. In The Netherlands, this is agreed upon by the health insurance companies: they pay ‘patient confidants’ because they are believed to promote better health outcomes.

Differences in funding exist between organizations. Some service user and carer associations are self-funded while others receive some government support. Some of the association accept sponsoring from pharmaceutical companies while others are strongly opposed to this. It became apparent throughout the conference that the role of the pharmaceutical sector is controversial and should be thoroughly explored. For now, transparency about their role seems all-important.
Conclusions

At the meeting, a great variety of stakeholders participated and all got a voice. It has been acknowledged by the participants that it was unique that family organizations, user organizations, service providers and policy makers were joined at the conference in an equal way. The level of confidence and expertise has grown over time and the climate is now one of openness. Collaboration is a key way to achieving empowerment.

The role of the WHO was conceived as acting as a catalyst of change, by facilitating good practice, capacity-building and supporting the process of empowerment. One way to do this is by supporting the implementation of the WHO-EC Statement on User Empowerment in Mental Health and by dissemination the presented indicators for user empowerment. These indicators have been accepted by the delegates, and one of the future tasks will be their implementation at country level.

The meeting provided a strong set of conclusions that have the potential to enhance service user and carer empowerment in mental health.

1. **Keep the empowerment debate alive**
   - Provide opportunities for regular exchanges of information and mutual support;
   - Show equal respect to everyone: service users, family members, professionals, policy makers.

2. **Make sure people have a voice and ensure this voice is heard**
   - Provide resources
     - Establish funding mechanisms for service user and carer associations
     - Reimburse expenses to make sure user and carer representatives from a wide range of countries can be equally involved
     - Ensure that service user researchers have control over some of the resources
   - Establish training and career paths including equitable payment systems;
   - Promote service user and family carer involvement
Reach consensus on what service user involvement means
Take evidence produced through service user research seriously and implement it in policy initiatives
Consider how service user expertise can be used
Address large disparities in power between mental health professionals and service users and carers

3. **Install quality assurance procedures**
   - Test and validate the indicators in some selected countries;
   - Conduct a basic survey in user and carer associations in Member States to assess how far empowerment has been included in policy and implemented in practice;
   - Implement the indicators at the national level;
   - Establish independent review bodies for quality assurance and protection and promotion of human rights of people with mental health problems.

4. **Produce dissemination procedures, guides and toolkits on:**
   - How to develop good local indicators;
   - How to implement the indicators;
   - How to design healthy workplaces;
   - How to design empowering services;
   - WHO to develop tools for empowerment activities jointly with Collaborating Centres and support implementation in countries.

5. **Disseminate good practices**

6. **Support leadership trainings for users and carers**

7. **Establish national mental health councils with diverse stakeholders**

8. **Make actions visible and understandable to all parties**
9. Pay attention to the translation of important documents

• In order for people to use and implement good practices, they should be able to read the information in their mother tongue.

The responsibility to realize these actions lies with the WHO Regional Office for Europe, with governments and with user and carer associations. The Regional Office will incorporate the development of these actions within the framework of its forthcoming European Mental Health Strategy; a European survey of user and family experiences of empowerment in countries is in preparation and will form part of the consultation process towards the new Mental Health Strategy.
References


