4th WHOCC (Lille, France) International Congress (30 and 31 January 2014)

Mental Health in Europe:
Recommendations for mental health service users' and carers' empowerment in mental health

"Empowerment means taking power, not just learning about it"
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The proceedings of the congress are available on the WHOCC (Lille, France) website:

http://www.ccomssantementalelillefrance.org/
A EUROPEAN CONGRESS ON THE EMPOWERMENT OF MENTAL HEALTH SERVICE USERS AND CARERS

On 30 and 31 January 2014, the 4th World Health Organization Collaborating Center for research and training in mental health (WHOCC, Lille, France) International Congress took place, which was an opportunity to stake out new orientations to support the empowerment of mental health service users and carers (Programme available on WHOCC website: http://www.ccomssantementalelillefrance.org).

Over 400 people, with more than half being mental health service users and carers, from 16 European, African and American countries, discussed how to empower users and carers during this Congress. European representative organizations, ENUSP for users and EUFAMI for families and carers, together with French national associations, Fnapsy, Argos 2001, France-Dépression, Advocacy-France and Unafam, participated in the presentations and discussions and made substantial contributions and proposals.

A number of representatives of user and carer organizations from Greece (SOFPSI and EPAPSY), England and Wales (Hearing Voices Network), the Netherlands (Amsterdamse Vriendensten, Mind Rights), Belgium (Psytoyens), Canada (Les porte-voix), Morocco (Association des usagers de la psychiatrie and AMALI), as well as umbrella organizations representing mental health associations in Belgium (AIGS) and the Netherlands (GGZ Nederland) provided a wealth of points of views and practices.

Other non-governmental organizations, such as Mental Health Europe, the British Mental Health Foundation, the International Mental Health Collaborating Network (London) and the Association of mental health service users of Quebec also participated, as well as a large number of representatives of universities, such as the University of Birmingham, the University of Brunel, the University of Cambridge, King’s College London and the Nottingham School of Nursing (England), Nova University of Lisbon (Portugal), the University of Stockholm (Sweden), the University of Montreal, the University of Sherbrooke and the Douglas Mental Health University Institute (Canada), Yale University (United States) and the Faculty of Medicine of Casablanca (Morocco). Elected officials and representatives from the Tunisian Ministry of Health, the French Ministry of Social Affairs and Health, the Regional Health Authorities for the Nord-Pas-de-Calais Region and the Mayor’s Office of the town of Hellemmes also demonstrated their support by contributing to the success of this Congress.
Finally, representatives and speakers from the World Health Organization Collaborating Centers in Ankara, Geneva, Montreal and Trieste also played an active role during the Congress.

A working session on the revision and development of the International Classification of Diseases was also organized in conjunction with the Congress, with the effective participation of users and carers.

**Mental health policy in Europe**

Jürgen Scheftlein, Policy Officer in charge of the Mental Health Unit at the European Commission, Directorate-General for Health and Consumer Protection, emphasized the importance of giving a voice to users, in order to ensure that their knowledge and expectations are taken into account. He specified that a common timetable will be established for mental health with the World Health Organization (WHO) and drew attention to the ongoing work of Pr. José Miguel Caldas de Almeida (Portugal) aimed at promoting a common understanding of community mental health services. He announced that the European Commission would support the development of these services.

Matthijs Muijen, in charge of mental health at the WHO Regional Office for Europe indicated that the Regional Office for Europe is mandated by the WHO to implement actions to promote human rights and empowerment in Europe. He stressed the importance to keep in mind the distress of the various populations and the diversity of situations of users of mental health services in Europe. The priority should thus be given to low income countries, where the challenges are greater. This was reaffirmed by Jürgen Scheftlein. Matthijs Muijen put forward the United Nations Convention on the Rights of Persons with Disabilities and the WHO European Mental Health Action Plan, in which the principles of dignity, safety and respect between services and users are promoted. He also insisted on the strength of common recommendations that could influence mental health policies, instead of focusing on differences between people and opinions. In conclusion, he underlined the importance of working together, such as during the Congress, with a common intention that would give strength to messages already adopted by ministries.
Objectives of this report

This report presents the background to the collaborative programme of work of the World Health Organization (WHO) and the European Commission (EC) on the empowerment of mental health service users and carers.

Subsequently, recent developments in connection with the Lille Congress are described, with a section on the pilot survey on empowerment indicators, followed by the work done on recommendations. In this report, the term “carers” is global, including family carers and informal carers, friends, etc. However, some results (WHO-EC indicators for example) target families specifically.

Finally, key conclusions of the Congress and prospects are discussed.
EUROPEAN RECOMMENDATIONS FOR THE EMPOWERMENT OF MENTAL HEALTH SERVICE USERS AND CARERS

Two working areas were chosen for the Congress. Firstly, a survey was designed with all of the partners involved based on empowerment indicators and, secondly, a series of commonly agreed recommendations for the empowerment of mental health service users and carers was drafted.

Introduction to the survey and initial results

In 2009, the World Health Organization (WHO) and the European Commission launched “The WHO-EC Partnership Project on User Empowerment in Mental Health”, consisting of four components:

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

The WHO Statement of Empowerment in Mental Health launched in 2010 entitled "User empowerment in mental health - a statement by the WHO Regional Office for Europe" gave a definition of empowerment¹ and proposed actions in 5 key areas:

- Protecting the human rights of service users and fighting against stigma and discrimination;
- Ensuring high-quality care and accountability of services;
- Having access to information and resources;
- Inclusion in decision-making
- Having local organizational capacity to make demands on institutions and governing structures.

The recommendations for action plans to be implemented apply at different levels: the societal/structural level, at the level of service provision and development, education and training of professionals, users, carers and society on the whole and finally, at the individual level.

¹ “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.”
On the basis of this Statement, the WHO Partnership Project developed 19 empowerment indicators which cover four main areas:

- Protecting the human rights of service users and fighting stigma and discrimination;
- Inclusion in decision-making
- Ensuring high-quality care and involvement in monitoring services;
- Having access to information and resources.

Another objective fulfilled in connection with this project was the collation of 100 examples of empowerment-based practices throughout Europe. Several of these practices were presented at the Leuven Congress in Belgium on 27 and 28th October 2010, “Empowerment in mental health - Working together towards leadership”, where government representatives and other relevant stakeholders came together, along with national and local mental health champions to discuss how concrete action can be undertaken to create an empowering environment.

The Leuven Congress concluded with the importance of developing and testing the empowerment indicators in order to be in a position to apply them at a practical level in connection with quality assurance procedures and to foster the protection of human rights.

During the preparation stage for the Lille Congress, the WHO Collaborating Centre (WHOCC Lille, France) rolled out an initial version of the survey with these 19 indicators. One or several target questions and an area for free comments were designed for each of the 19 indicators to allow a more detailed answer. The survey was reviewed by international and national mental health stakeholders. Then it was widely distributed in two versions: paper and web (see the link below)

http://enquetes.epsm-lille-metropole.fr/ccoms/empowermentccoms/questionnaire.htm

This survey had several objectives, including to:

- Benefit from the point of view of users, families and carers, as well as all people participating in the health system (health professionals, social services professionals, elected officials, members of non-profit organizations, etc.)
- Survey all the European countries
- Test the empowerment indicators and target questions
- Collect examples of good practice for the empowerment of users and carers in mental health
- Formulate concrete and applicable recommendations.
The initial results and limitations encountered were presented at a plenary session of the Congress.

One of the major limitations of the survey was its complexity. It was found to be too long due to the number of items (indicators + sub-indicators), as well as the need to distinguish between users and carers for each indicator which discouraged certain respondents. The “Yes/No/I don’t know” format for answers was not always appropriate to respond to certain items. Finally, another limitation having an impact on the results is the fact that French respondents were over-represented compared to respondents from other countries.

However, over 350 people from 27 countries answered the survey with a good level of participation of users (nearly 20% of respondents) and carers (20%) and of professionals (40%).
A few examples of the results

Results of four indicators are presented in this report. Full results for the 19 indicators are available on the WHOCC (Lille, France) website:

http://www.ccomsantementalelillefrance.org

Reading guide for tables

Results for four of the questions contained in the survey are presented below. For each indicator, the left table shows data for France versus all other countries and the right table shows data according to the three categories of respondents (Users, Families and Professionals), for all countries taken together.

The colour code for answers given (yes, no, I don’t know) is indicated between the left and right tables.

In reading these tables, limitations previously stated must be kept in mind. These results are avenues for further reflection.

A gap between the perceptions of the different categories of respondents seems to persist regarding rights or involvement in care and service organizations.

Indicator No. 4:
The country has employment legislation to cover the needs of family carers.

Other than the clear answer provided by families, the lack of information regarding knowledge of existing legislation should be underlined.
Indicator No. 7:
People with Mental Health problems and their families and carers have access to appropriate Mental Health services.

Here there is a wide gap between the perception of professionals on the one hand, and users and families on the other hand.

These results show disparities between countries, a lack of knowledge of rights, and insufficient information provided according to respondents.

Indicator No. 16:
16a. Public funds are available for mental health service users' organizations.

The lack of knowledge regarding the availability of public funds is higher in France, but remains significant for each category of respondent.
Indicator No. 18:
18b. Adequate education is available for families and carers of people using mental health services to support them in their role as carers.

Even if families seem to be better informed, results diverge among countries.
Protocols for deriving recommendations

This Congress was an opportunity to compare the different points of view of all of the stakeholders: mental health service users, carers, professionals and elected officials.

Recommendations for the empowerment of mental health service users and carers were proposed by the participants throughout all stages of the Congress - from the preparation stage (via the numerous offers for presentations received and from the Scientific Committees) up to the actual plenary sessions and workshops - not to mention on-going participation in the online Survey throughout this time. Ultimately, 200 recommendations were collected.

Initial work to classify and summarize the proposed recommendations led to the identification of 21 areas of work, grouped into 3 categories:

- Protection of Human Rights
- Participation in the organization and evaluation of services
- Information and communication

Other bibliographical resources were consulted for the purposes of this report:

These documents, and the numerous examples of good practices collected in connection with the Congress, were used to define and illustrate the 21 recommendations.

This Report was then presented to the Lille WHOCC's Scientific Council during the meeting held on the 2nd of April 2014 in Paris, and subsequently to the partners involved (ENUSP, EUFAMI, Local Organizing Committee of the Congress, steering group of the empowerment project of WHOCC (Lille, France), International and French experts, WHO Regional office for Europe and the European Commission).
21 recommendations to empower mental health services users and carers

Defend Fundamental Rights

1. Protect fundamental rights in mental health and social care facilities.
2bis. Ensure such rights are enforced and provide and implement penalties in the event of violation.
2. Guarantee the self-determination and the legal capacity of users and carers.
3. Defend full citizenship of users and carers.
4. Supply the resources for users and carers to be free to call on the health care and social service providers of their choice.
5. Identify, in order to restrict, the use of isolation and restraint.
6. Assess, in order to limit, the use of compulsory psychiatric care.
7. Develop services in the community close to where people live and encourage alternatives to hospitalization.
8. Develop legal aid systems for users and carers, including persons imprisoned.
9. Guarantee access to mental health services in prisons.

Participate in the organization and evaluation of services

10. Ensure the effective participation of users and carers at all levels and guarantee the conditions for their effective participation.
11. Assess the quality and organization of services and patient safety using instruments designed together with users and carers.
12. Include the contribution of users and carers in both initial and on-going training programmes designed for mental health professionals, as well as in research.
13. Encourage cooperation in the field of prevention at the level of local territories, together with users, carers, professionals, social workers, elected officials and wider civil society.
14. Ensure that users' and carers' organizations have their place in mental health services.
15. Develop networks and mutual support groups (clubhouses, "Groupes d'entraide mutuelle" in France, etc.).
Inform and communicate

16. Provide and widely disseminate appropriate information on mental health using different media: print, images, films, social networks, blogs, etc.

17. Provide and widely disseminate international conventions and treaties that apply to the human rights of mental health service users.

18. Make information accessible on the actual supply and demand of mental health services in given territories.

19. Create an observatory of empowerment of users and carers, with an international database of assessment tools.

20. Create observatories to monitor how the media treats information on mental health issues and encourage a response from users and carers.

21. Recognize and promote the fact among the general public and health professionals that users and carers are experts by experience.
PHILOSOPHY AND FUTURE PROSPECTS

The empowerment of users and carers will require other changes in the mental health field.

Firstly, mental health and social care services must facilitate empowerment by implementing shared care processes, by providing information and by allowing the involvement of users and carers in the organization of their services. Services need to change their practices in a way that integrates the opinions of users and carers when it comes to the care and services offered to them. Users and carers also need to be involved in the quality control process of services. An effort to ensure the effective recognition and the exercise of human rights by users of services, both in hospital and community-based services is necessary. Active mental health promotion and prevention strategies, designed together with users and the community are also required. A fundamental change of attitude is needed leading to open services, the least coercive possible, and reducing the use of compulsory care (such as the Trento example in Trieste, Italy).

Then, fighting against stigma and its negative impact must continue at the same time. Examples of celebrities, elected officials or health professionals who announce their coming-out and events such as “Mad Pride” are vehicles for change. Recommendations from the ASPEN programme (Anti Stigma Programme European Network, www.antistigma.eu) are aimed in the same direction.

But the most important factor is the concrete change through application of the twenty-one recommendations proposed in this report. They are the result of the work undertaken by the WHO, the European Commission and NGOs consisting of users, families and carers throughout Europe. They must be circulated and evaluated at European level. Empowerment is a generic term, efforts must be made at different levels. Collective empowerment level should aim at political and social changes. Individual empowerment should foster capacity of choice and autonomy. It seems essential to identify the level of intervention and target (mental health services users, carers, peer workers, …) in order to implement effective actions.

The role of the WHOCC (Lille, France) to promote the mainstreaming of good practices in community-based mental health services that take into account the empowerment of users and carers and to establish recommendations for mental health services at community level in Europe was greatly supported during this Congress by both the WHO and the European Commission.
The WHOCC (Lille, France) would like to invite organizations representing mental health service users and carers throughout Europe to participate in the creation of a European observatory of best practices in the field of empowerment of mental health service users and carers.
DETAILS OF RECOMMENDATIONS AND EXAMPLES OF GOOD PRACTICES

Defend Fundamental Rights

1. Protect fundamental rights in mental health and social care facilities.

1bis. Ensure such rights are enforced and provide and implement penalties in the event of violation.

References:
- CRPD (Convention on the Rights of Persons with Disabilities)
- QualityRights Programme (WHO)
- French psychiatric hospital county-level inspection boards ("Commissions Départementales des Soins Psychiatriques")
- French High Authority for Health ("HAS") certification process

Examples of good practices:

- **QualityRights, Greece**: Using the WHO QualityRights tool to assess practices in mental health facilities on the basis of international human rights standards derived from the Convention on the Rights of Persons with Disabilities.
  

- **QualityRights, Greece**: Utilisation de l’outil Quality Rights de l’ OMS pour le monitoring et l’évaluation de la violation des droits des usagers et la qualité des soins comme pratique de « routine », dans le cadre des structures résidentielles et des appartements communautaires de l’ONG EPAPSY avec la participation des usagers.
  

More information on QualityRights:

http://www.who.int/mental_health/policy/quality_rights/en

- **FRA Research Project**: Fundamental Rights Agency (FRA) Research Project on the Rights of People with Intellectual Disabilities and People with Mental Health Problems. The project aimed to assess the fundamental rights situation of some of the most vulnerable groups of persons with disabilities, namely those with intellectual disabilities and those with mental health problems.
  
  Reference: http://fra.europa.eu
• **Commissions for relations with health care service users and for the quality of care (CRUQPC), France:** Their objective is to ensure compliance with patients' rights and facilitating their administrative procedures.

  **Reference:** Article L.1112-3 of the French Public Health Code: "All health care facilities shall establish a Commission for relations with health care service users and for the quality of care. This Commission shall be in charge of ensuring that the rights of health care users are complied with and of contributing to improving the quality of the reception offered to persons who are ill and their families and the quality of their care. This Commission shall facilitate the administrative procedures of these persons and when necessary, ensure that they are able to express their complaints to the relevant persons in charge in these facilities, hear their explanations and be informed of the follow-up given to these complaints."

2. **Guarantee the self-determination and the legal capacity of users and carers.**

  **References:**
  - Article 13 of the Convention on the Rights of Persons with Disabilities
  - Part 5 of the French Government report on health care service users' rights "Usagers de la santé, votre santé, vos droits"

  **Example of good practice:**

  • **IMHA, United Kingdom:** National clinical study on the experience of IMHA (Institute of Mental Health Advocacy), an independent institute providing legal aid for mental health service users, for the purpose of collecting good practices in the field of advocacy and legal aid designed for persons incarcerated.

    **Reference:** Newbigging K. The Right to be Heard: an evaluation of statutory mental health advocacy.

  • **PO-Skåne, Sweden:** This ombudsman service is for users of psychiatry and particularly those who are isolated and the hardest to reach, usually left without support. Designating a PO to advocate for your rights may be done anonymously and is a very simple process based on trust over time. PO-Skåne started as a project with two POs and today has a permanent user-run service of three hundred POs working full time in the Malmo area.

    **References:**
    - [http://www.youtube.com/watch?v=t6scSjDq21I](http://www.youtube.com/watch?v=t6scSjDq21I)
3. **Defend full citizenship of users and carers** (access to housing, employment, bank services, etc.).

**References:** Article 27 of the Convention on the Rights of Persons with Disabilities

ASPN Programme ([www.antistigma.eu](http://www.antistigma.eu))

**Examples of good practices:**

- **Project for a comprehensive revision of the public mental health care model based on the WHO QualityRights project, Canada:** QualityRights is a tool kit providing countries with practical information and tools for assessing and improving quality and human rights standards in mental health and social care facilities. The objective is to take concrete steps by assessing and improving the quality and human rights standards both in hospital and outpatient services. Persons with lived experience of mental health problems can contribute and even exercise leadership in this area.


- **Mobile polling stations, Canada:** Improving access to voting rights of persons with disabilities by election officials who provided new voting methods, such as mobile polling stations or voting by mail.


- **Sick leave, Netherlands, United Kingdom:** Establishment of sick leave system for carers.

  **Reference:** [https://www.gov.uk/time-off-for-dependants/your-rights](https://www.gov.uk/time-off-for-dependants/your-rights)

- **Tax credit, Canada:** Agreement on tax credit for persons with disabilities, transferable to caregivers, payment of monthly benefits to caregivers (Nova Scotia).


4. **Supply the resources for users and carers to be free to call on the health care and social service providers of their choice.**
5. Identify, in order to restrict, the use of isolation and restraint.

Examples of good practices:

- **AGIDD-SMQ, Canada**: Drafting of a document containing information, opinions and recommendations aimed at eliminating coercive measures (physical restraints and forced medication, isolation) by the Quebec NGO composed of intervention groups to defend the rights of mental health service users - "AGIDD-SMQ" (Association des Groupes d'intervention en défense des droits en santé mentale des usagers du Québec). Reference: Ensemble pour s'en sortir et s'en défaire, Réflexions et recommandations visant l'élimination des mesures de contrôle: contention, isolement et substances chimiques. 2006. [www.agidd.org](http://www.agidd.org)

- **Cross audit, France**: Performance of a cross audit at the request of users on the use of isolation and restraint in all hospitals in the Nord-Pas-de-Calais Region. Reference: [http://www.santementale5962.com/nos-travaux/l-audit-croise-interhospitalier/article/isolement-therapeutique](http://www.santementale5962.com/nos-travaux/l-audit-croise-interhospitalier/article/isolement-therapeutique)

- **ARGUS, Netherlands**: Argus is a nationwide database in the Netherlands in which data is stored on interventions that limit or restrict the client’s freedom of movement, such as seclusion, restraint, forced medication and force-feeding. Reference: Boogaarts, J. (2012), Registratie van vrijheidsbeperkende interventies is de geestelijke gezondheidszorg [Registration of restraining interventions in mental health care], GGZ Nederland 2012.

6. Assess, in order to limit, the use of compulsory psychiatric care.

Examples of good practices:

- Include the reflexion on the change in compulsory psychiatric care in the certification of hospital and out-patient services.

- Establishing a system for early verification by the judicial authorities and prevention of compulsory psychiatric care measures.


7. Develop services in the community close to where people live and encourage alternatives to hospitalization.

Examples of good practices:

- **Eindhoven Model, Netherlands**: This model supports decision-making using the “Family Group Conferencing” system to prevent mental health crisis situations - a powerful alternative method to avoid compulsory psychiatric care. 
  

- **Mental health Reform (Art 107), Belgium**: This reform is based on a community approach which aims to provide care in the environment of the person and this as an alternative to hospitalization.
  

- **EPAPSY, Greece**: Mobile mental health care teams. Good practice of mobile mental health teams in remote areas (the Cyclades).
  

- **FACT, Netherlands**: Flexible Assertive Community Treatment teams provide long-term care for people with severe mental health problems. FACT provides treatment, guidance and practical assistance with daily living, rehabilitation and recovery support, with the aim of ensuring continuity of care, preventing admissions to psychiatric hospitals and stimulating inclusion in society. The FACT teams are decentralised in districts and work closely with other local and neighbourhood organisations. There are currently over 200 FACT teams in the Netherlands, but it is expected that this number will rise to 400-500 in the near future.
  
  **References**: CCAF (2013), [Online], Available: [www.ccaf.nl](http://www.ccaf.nl).

- **Use of community ressources, Greece**: Primary care practitioner (WHO Mental Health GAP training tool) or local religious leaders (organized training in Cyclade islands).
  
8. Develop legal aid systems for users and carers, including persons imprisoned.

Reference: Article 13 of the Convention on the Rights of Persons with Disabilities

Example of good practice:

- **Ombudsman, Netherlands:** Since 1993, Dutch law obliges every psychiatric hospital to have an independent user advocate and independent carer advocate. These advocates are employed by an independent trust/foundation and work for free. They are required to respect patient confidentiality.


9. Guarantee access to mental health services in prisons.
10. Ensure the effective participation of users and carers at all levels and guarantee the conditions for their effective participation:
   i. appropriate financial support.
   ii. quality control based on tools designed with users and carers.
   iii. guarantee the use of evidence-based methods of participation.

References:
- Article 29 of the Convention on the Rights of Persons with Disabilities
- Data Sheet 26 (Part 5) of the French Government Report on health care service users' rights “Usagers de la santé, votre santé, vos droits”
- Recommendations 1, 2, 5, 7, 8 and 9 of the Compagnon Report

Examples of good practices:

- **Mental health Reform (Art 107), Belgium**: In 2010 when Article 107 of the Law on hospitals came into force implementing a new stage in mental health care reform recommending the organization of community-based health care focused on the needs of patients close to where they live. Special financing has been earmarked to enable representatives of users and families to carry out specific "missions" negotiated with and laid down in a contract signed with the Ministry of Social Affairs and Public Health.
  

- **Regional Health and Autonomy Groups (CRSA - "Conférences Régionales de la Santé et de l'Autonomie"), France**: In charge of organizing a public debate on health issues of their choice. The opinions of the CRSA are made public. These groups provide a forum for users of the health care system to express their opinions, and are in charge of assessing the conditions under which the rights of patients and users of the health care system are applied and respected, ensuring equal access to health care services and the quality of health care.


Suggested tool:

| Scale of participation in the decision-making process at 5 levels (developed by the LPGGZ, Netherlands). |
|---|---|
| 1- users are informed |
| 2- users are consulted |
| 3- users advise |
| 4- users are fully involved: joint initiatives, cooperation and shared decision-making |
| 5- users take initiatives to design and manage certain aspects themselves |

Within mental health care facilities, the highest level of involvement possible may be decided for each subject or issue. This should be decided with a committee made up of users and/or family members.
11. Assess the quality and organization of services and patient safety using instruments designed together with users and carers.

References: Data Sheet 16 (Part 3) of the French Government Report on health care service users' rights “Usagers de la santé, votre santé, vos droits” Recommendations 3, 4 and 5 of the Compagnon Report

Examples of good practices:

- **Safety audits, Netherlands:** A pilot programme of safety audits performed in 5 mental health facilities performed by auditor users and carers trained by the National Mental Health Care Platform.
  Reference: [http://www.platformggz.nl/lpggz/organisatie/de_mensen](http://www.platformggz.nl/lpggz/organisatie/de_mensen)

- **Routine Outcome Monitoring, Netherlands:** A programme to monitor the quality of care, via a questionnaire for users designed by peer-advocates, with results reported and exploitable by all players.

- **Participative self-evaluation, United Kingdom:** Self-evaluation of the side effects of antipsychotic medication, measured based on current knowledge, that can be used for research and clinical work using an innovative participative methodology to maximize the participation of service users.

12. Include the contribution of users and carers in both initial and on-going training programmes designed for mental health professionals (doctors, nurses, psychologists, social workers, etc.), as well as in research.


Examples of good practices:

- **HAFAL, United Kingdom:** Research Development Groups in partnership with service users and health professionals to design and develop health and social care research financed by the Mental Health Research Network (Hafal, Involving People) and the University of South Wales.

- **ARUCI-SMC, Canada:** The International Alliance for university research with mental health communities and citizenship (ARUCI-SMC - Alliance internationale de recherche universités-communautés Santé mentale et citoyenneté) organizes partnerships between community-based organizations that represent a major source of innovation and knowledge based on practical experience and post-secondary schools that contribute a wide range of knowledge and skills in the field of social sciences.
  Reference: [www.ARUCI-SMC.org](http://www.ARUCI-SMC.org)
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E-mail : ccoms@epm-lille-metropole.fr Website: http://www.ccomssantementalelillefrance.org/

• **PICRI Study, France:** This programme was implemented via a partnership with the French AFTOC user’s organization for persons with Obsessive Compulsive Disorder, research teams, clinicians and therapists to deal with the public health problem of Obsessive Compulsive Disorder (OCD).


• **Revision of the ICD-10 (International Classification of Diseases), France:** A working group composed of users who are experts by experience and professionals who are members of the French-speaking group for the development of the ICD, coordinated by the WHOCC (Lille, France), to establish a working method that would allow users and carers to participate in the drafting of this upcoming revision.


• **Mental health Reform (Art 107), Belgium:** Within the global training of the Reform on mental health in Belgium, trainings are organized and delivered by users and families to the attention of professionals: psychiatrists, psychologists, social workers, nurses, ...


13. **Encourage cooperation in the field of prevention at the level of local territories, together with users, carers, professionals, social workers, elected officials and wider civil society.**

  *Reference:* Recommendation 6 of the Compagnon Report

**Example of good practice:**

- **Local Mental Health Councils, France:** These councils ("CLSM" - Conseils locaux de santé mentale) are joint platforms for consultation and coordination among local elected officials, public sector psychiatric services, users and carers. The objective of these Councils is to define local policies and action plans to improve the mental health of the general population. 90 such Councils have been set up and 70 are currently being created, involving over 300 counties now working together through these Councils.


- **Healthwatch, England:** Under the Health and Social Care Act 2012 which came into force in April 2013 local Healthwatch took over from Local Involvement Networks (LINks) as the statutory community, patient and service user champion. Each Healthwatch is commissioned by its borough or county council.

  *Reference:* Mental Healthwatch handbook : Improving mental health with your community, [http://www.nsun.org.uk/assets/downloadableFiles/mentalhealthwatchhandbookv1april20142.pdf](http://www.nsun.org.uk/assets/downloadableFiles/mentalhealthwatchhandbookv1april20142.pdf)
14. Ensure that users' and carers' organizations have their place in mental health services.

**Reference:** Recommendation 4 of the Compagnon Report

**Example of good practice:**

- **Wet medezeggenschap cliënten zorginstellingen, Netherlands:** This Client Representation Act demands that all health care organisations establish a consumer advisory board and develop internal regulations for its operation. The Act also regulates the board’s advisory rights and requirements on providers to keep the board informed.


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15. Develop networks and mutual support groups (clubhouses, "GEM" - *Groupes d'entraide mutuelle* in France, etc.)

**Example of good practice:**

- **Mutual self help groups, France:** 360 mutual support groups ("GEMs", Groupes d'entraide mutuelle) have been created in France, financed by the State and co-managed by user organizations.
Information and communication

16. Provide and widely disseminate appropriate information on mental health using different media: print, images, films, social networks, blogs, etc.

Reference: Article 21 of the Convention on the Rights of Persons with Disabilities

Examples of good practices:

- **Crisis Points, United Kingdom**: Creation of crisis points to manage mental health crisis situations that operate based on a recovery model with an informative approach and the empowerment of users. The use of the "Recovery Star" specially adapted evaluation tool can be used by users in crisis situations so as to identify their objectives and the progress made.  
  http://www.turning-point.co.uk/crisis-point.aspx

- **Psycem, France**: French mental health public information, communication and training agency offering documents, awareness campaigns and training to any person interested in mental health issues (patients, their families, professionals in the fields of health, social, and medical-social care, counsellors, elected officials, journalists, etc.). Psycem works with users' organizations to fight stigma of persons with mental health problems and their families.  
  Reference: http://www.psycom.org/

- **Stars Shine Brightly in the Sky, Malta**: Publication of a book designed for carers explaining the experiences of persons living with mental health problems. This book was co-produced by two Maltese NGOs (Mental Health Association and the St. Jeanne Antide Foundation).  

- **Mental Health Information Weeks (known as the "SISM" - Semaines d'Information sur la Santé Mentale in France)**. The SISM is an annual event coordinated by a group of nineteen partners who make up the Coordination Committee. Each year in the month of March, NGOs, members of civil society and professionals partner up to organize events targeting the general public to provide information, to debate and to promote mental health all over France. In 2014, over 800 events took place throughout the entire country.  
  Reference: http://semaine-sante-mentale.fr/

- Mental Health Weeks exist in a number of European countries (Scotland, England, Germany, Belgium, Spain, among others)

- **Scottish Mental Health Arts and Film Festival (SMHaff), Scotland**. This is a 3-week long (October) awareness raising and educational creative festival throughout the entire country.  
  Reference: http://www.mhfestival.com/
17. Provide and widely disseminate international conventions and treaties that apply to the human rights of mental health service users.

Examples of good practices:

- **Casablanca, Morocco**: Display of the charters defining the rights of in-patients in several languages inside the hospital and creation of a CD-Rom with international conventions on users rights and codes of ethics in psychiatry.

18. Make information accessible on the actual supply and demand of mental health services in given territories.

Examples of good practices:

- **ASPEN Programme (Anti Stigma Programme European Network)** - This research programme, funded by the European Commission and coordinated by King’s College London (UK), took place in 20 sites in 18 European countries over a period of 3 years (2009-2011). The overall aims of the ASPEN programme were to suggest a series of well-researched recommendations and actions to tackle the stigma and discrimination of mental illness and share best practices from all over Europe in this respect; encouraging access to and keeping of employment; formulating good practices in health policies and including civil society in health policy making; and collating experiences from people with mental health problems in order to better understand the extent, nature and contexts of their experiences. The ASPEN consortium consisted of university researchers, user and carer organisations, mental health charities and NGOs, public agencies, health professionals, and more, and is still active today.  
  

- **Health service user and carer information centres, France**: In hospitals and care facilities, these centres are called **Maisons des usagers**.  
  
  
• Regional Mental Health Research Federation Observatory (Observatoire de la Fédération Régionale de Recherche en Santé Mentale for the Nord-Pas-de-Calais Region, France) - This Observatory collates, processes and analyzes data available so as to improve knowledge in the field of psychiatry and mental health by selecting indicators relevant to health determinants, supply and demand of health care services, as well as psychiatric morbidity/mortality. This knowledge is mainly derived via exploitation of major data bases (number of people treated, number of hospitalizations, use of psychotropic medication, fatalities, use of emergency services such as ambulances for suicide attempts, etc.) and results from regional surveys among the general population (Surveys on the mental health of the general population, Health barometers, etc.). Users’ organizations are members of the Scientific Committee and data is publicly available.


19. Create an observatory of empowerment of users and carers, with an international database of assessment tools.

Examples of good practices:

• Value+ project: This project addressed the growing need realised by the European Patients’ Forum (EPF) and the European Commission (EC) to support the exchange of information and experience on good practices relating to patient involvement in EC projects.


20. Create observatories to monitor how the media reports on mental health issues and encourage a response from users and carers.

Examples of good practices:

• See Me, Scotland: The Scottish "See Me" campaign is a national programme for ending mental health stigma and discrimination. Among other action, the programme works in partnership with the media to educate and inform journalists using a variety of methods, including monitoring publications by the media.

Reference: www.seemescotland.org

• ESJL – AIAIP partnership, France: Establishment of an original partnership between the association of psychiatric interns and former interns and the journalism school (École supérieure de journalisme) of Lille with the objective to train journalists and future journalists in the basics of mental illness and psychiatry.

Reference: Ecole supérieure de journalisme de Lille (journalism school) : http://esj-lille.fr/etudes1
Association des internes en psychiatrie de Lille (AIAIP, association of psychiatric interns): http://aiapsy.wordpress.com
21. Recognize and promote the fact among the general public and health professionals that users and carers are experts by experience.

**Reference**: Article 26 of the UN Convention on the Rights of Persons with Disabilities

**Example of good practice:**

- **Peer workers, Italy, France, Canada**: Inclusion of peer advocates in mental health and social care facilities, such as the "User and Family Experts" (Italy), Peer Health Mediators (France), Peer Advocates (Canada).
  
  **Reference**: De Stefani R. The active involvement of users and family members in the Mental Health Service of Trento. The “doing together” approach and the Expert Users and Family members (UFE). Salute e Società, 2011, Franco Angeli, English version

- **Awakenings Foundation, Hungary**: This foundation started an online forum named mental health forum where over three-hundred professionals and users, experts by experience continuously discuss hot issues in mental health. When the government started to elaborate on a new National Mental Health Project in 2013, Awakenings Foundation organized 3 conferences, convening several hundred users, experts, political decision-makers to sit down around the same table and exchange ideas. No salary is paid to experts by experience and accompaniment, however the Foundation has started to get accreditation in educating these experts and intends to elaborate a regular vocational education for these people.
  
  **Reference**: http://www.sozialmarie.org/projekte/changing_the_attitudes_towards_people_with_mental_disorders.980.html?downloadType980=pdf_de&downloadFile980=519