

Mental health in the first person. Committees of experts

0. PRESENTATION

Surely it has happened to you. There comes a moment during the recovery and experience of a mental health problem in which we feel the call to participate. Then we become aware that we are part of a collective many times forgotten, and we decide to join forces.

The simple act of being on the way, of fighting, gives us hope, and we begin to look for answers that provide a solution to our needs and to our dreams of freedom. After all, aren't we all recipients of the same rights, those which entitle us to dignity?

Perhaps this is the greatest challenge: How to transform our ideals into a living, vibrant, fair and inclusive social reality? There are so many of us asking for an opportunity to go beyond the forbidden fulfilment, and yet there is so much emptiness.

We do not like silence, nor that we put down our our arms, or forget our image, because we are a living, human group, cultivating the consciences of those who look away from a problem they say is not theirs.

There is so much potential in people, and there is so little attempt to enlighten it, that we run the risk of getting used to living in no man's land, far from the dialogue that leads us to understanding.

The time has come to read the script of our lives and become the protagonists, feeling the encouragement of those who still wear the light of humanity.

It is true. Every time you take on a challenge, what you really do is give yourself an opportunity. Therefore, we are going to fill the white book of destiny with challenges and desires, because those who have lost everything have nothing to lose. Where there should have been an independent life project, now there is only the echo of a desperate voice. We have to change our circumstances.

We are going to live the process of empowerment as if it were an adventure, the adventure of knowledge. If we value our experience, the roads will widen.

We have to overcome that resistance that is conformism and silence, and be the change we want in the world.

From the Pro Mental Health In First Person Committee, we send all our energy, in the assurance that together, we will open the doors to the future, and no one will be more than anyone else.

We all have the right to quality healthcare, but also to a psychosocial role that defines us.

From words, justice will be born.

Basilio García Copín
Coordinator of Committee of experts
MENTAL HEALTH SPAIN

1. Introduction

There are **multiple barriers** that impede the right to participation of people with mental health problems, such as prejudice, discrimination, labels, paternalism, lack of information and training, traditionalism or scepticism. The fact of being able to participate in decision-making offers a multitude of advantages both from the perspective of rights as well as for empowerment and rehabilitation.

Participation is a recognized right. Although, unfortunately, participation in mental health is still scarce, at MENTAL HEALTH SPAIN it is considered essential to promote the real and effective involvement of all the people who, at some point in their life, may be affected by mental health problems.

The MENTAL HEALTH SPAIN Confederation is a non-profit organization of social interest and declared of public utility that was founded in 1983 and whose **mission** is to improve the quality of life, defend the rights of people with mental illness and their families and represent this associative movement. Currently, it integrates 19 regional federations and single-province associations, which in turn bring together almost 300 associations and add more than 44,000 members in the entire state territory.

According to the PARTISAM Guide, a tool for the promotion of the participation of the users of the mental health services coordinated by the Confederation and edited by the Spanish Association of Neuropsychiatry (AEN), the **participation** *"entails personal decision-making, which enables the person to have control over their own life. That is, facilitate the empowerment of people with mental health problems, and that of their families as caregivers."*

The World Health Organization (WHO) considers that **"empowerment"** is an essential concept of health promotion. Since the Declaration of Alma-Ata (WHO, 1978) it has been recognized that *"people have the right and duty to participate individually and collectively in the planning and implementation of their health care"*.

Applied to people with mental health problems, the WHO states that *"in the context of **mental health**, empowerment refers to the level of choice, influence and control that users of these services exercise in the situations that occur in their lives"* (OMS, 2010). That is why it is so important to facilitate that these people take the reins and lead the initiatives, proposals and actions that are carried out in all aspects related to the defence of their rights and their quality of life and wellbeing.

WHAT IS EMPOWERMENT?

Decalogue "*What is empowerment?*" (2014).

Mental Health in the First Person Committee of MENTAL HEALTH SPAIN

FULFILMENT. The life of people has multiple facets, and we want to enjoy all of them.

CONTROL. We want to be the protagonists of our experiences.

IMPROVEMENT. We want to enhance our skills.

RESPONSIBILITY. We want to value our maturity, without paternalism.

AUTONOMY. We want to close the loops of work and affection.

WELLNESS. Both on a social and individual level; we want to be happy. We must humbly accept our limitations to avoid unnecessary frustrations.

CONFIDENCE. At the same time we must transmit security when it comes to socializing, without complexes.

SELF-ESTEEM. (Of great therapeutic value)

PARTICIPATION. "Nothing about us without us."

The **stigma** is one of the fundamental invisible barriers - if not the most important - that people with mental health problems have to overcome to make their rehabilitation process possible.

One of the best ways to combat it is by getting to know first-hand the people who have had or have these problems, by listening to their voices and their experiences. This is how "*the others*" becomes "*we*", since there are more things we have in common than those that separate us, and not only because one out of every four people can develop a mental health problem throughout their lives, but because all of us, as citizens, have the same rights and obligations.

2. What is the Pro-Mental Health in the First Person Committee?



For

"The key to empowerment is the elimination of formal and informal impediments, as well as the transformation of power relations between individuals, communities, services and governments" (WHO, 2010). With that in mind, MENTAL HEALTH SPAIN, wanted to transform these relationships by promoting the creation of Committees formed by people with their own experience in mental health since 2009.

These Committees are formed by people with mental health problems who actively participate in the life of their associations and who believe in the motto "*nothing about us without us*", on the basis that the experience itself provides a fundamental point of view when analysing and defending the rights of this group and their families.

With the creation of the Committees, the strong commitment of the governing bodies of the Confederation to promote and facilitate the real participation of people with mental health problems in their functioning and decision making is materialized.

There is a Committee at the state level, composed of representatives of each of the autonomous entities that are members of the Confederation. In turn, these organizations have gradually created their own committees at the regional level.

The Mental Health in the First Person Committee advises the governing bodies, develops proposals, proposes projects, establishes positions and gives voice to people with mental disorders, both for the organization and for society in general.

Among others, its functions are to discuss and study issues of interest to people with these health problems and to establish positions in this regard, promote employment, exchange experiences and good practices developed in the autonomous communities, fight against stigma and develop an agenda of claims and strategies to follow.

In line with the philosophy of both the Committee and the Confederation itself to offer a positive vision of mental health, at its last meeting the members of the Committee decided to change its name, replacing "mental illness" with an expression that emphasizes both the person's own experience and the concept of health rather than disease, and renamed it the Mental Health in the First Person Committee.

2.1. Objectives, regulation and organization

According to the internal regulations prepared by the Committee itself and approved by the Board in 2010, to be part of the Committee it is necessary that there is a formal designation by the autonomous entities. Currently, except for one, there is representation of all the autonomous communities.

In order to carry out its functions, the Committee meets in person twice a year, and on a non-contact basis, as many times as necessary. In the meetings decisions are taken by consensus, and if there is no agreement, the regulation contemplates that they are adopted by simple majority.

2.2. A bit of History: the beginnings of the Mental Health in the First Person Committee

On **January 20, 2009 a working group was set up** in which the participation of people with mental illness in the associative movement grouped under MENTAL HEALTH SPAIN was discussed.

In this debate, the 15 attendees expressed their opinion about what participation is, what their participatory experience was in their own association or federation, the difficulties they encountered in participating and which aspects could favour it.

The minutes of that meeting, with all the proposals and conclusions, were sent to the Permanent Commission of the Confederation, which, after careful reading, finally proposed **the creation of an Advisory Committee of People with Mental Illness, an initiative that was approved by the Board of Directors on February 21, 2009**. Some participants in the first working group participated in the XVI CONFERENCES OF FEAFES, held in Cuenca from **22 to 24 October** .

Once the process of appointing regional representatives was completed, on **September 21, 2010** , **the first meeting of the recently established Committee on Persons with Mental Illness** was held at the headquarters of MENTAL HEALTH SPAIN, which, as an advisory body, was already part of the structure of the Confederation.



This first meeting was attended by twelve representatives appointed by nine federations and single-province associations integrated in the Confederation: FEAFES Andalucía, FEAFES AFESA Asturias, FEBAFEM (Balearic Islands), ASCASAM (Cantabria), FEAFES Castilla y León (now Castilla y León Mental Health Federation), FECAFAMM of Catalonia (now Federació Salut Mental Catalunya), FEAFES Extremadura (currently FEAFES Extremadura Mental Health), ANASAPS (Navarra), ACEFEP of Ceuta (now Ceuta Mental Health Association), and a guest by the, then, FEAFES Confederation.

In this meeting, the representative of Ceuta, Basilio García Copín, was appointed as the person in charge of the Committee and the representative of Castilla y León, Elena Briongos Rica, as secretary.

In the Board of Directors of the Confederation of **December 11, 2010**, **the Committee's internal regulation was finally approved unanimously**.

Among other activities, described below, members of the Committee participated in the preparation of the **Strategic Plan 2012-2016** of MENTAL HEALTH SPAIN, just as they are doing in the current Plan, which will be effective as of 2019. As indicated in this Strategic Plan, the participation of people with mental health problems is the basis of one of the main strategic lines, concerning the social and political impact of the Confederation.

2.3. A bit of History: a walk through the main activities carried out

Since the Committee's inception, its actions have revolved mainly around the defence and exercise of the rights of people with mental health problems, the elimination of invisible barriers that hinder full social participation and the implementation of strategies with which to encourage the creation of networks and the strengthening of the associative network.

The FEAFES Congress held in Valladolid on May 5, 6 and 7, 2011 was one of the first major milestones for the Committee as it shared with the associative movement its vision and proposals on employment, implementation of the Mental Health Strategy of the National Health System, and application in Spain of the UN Convention on the Rights of Persons with Disabilities.

In November of that same year and at the request of the Confederation, Elena Briongos **began to participate** together with the president of MENTAL HEALTH SPAIN, **in the Committee of Follow-up and Evaluation of the Mental Health Strategy of the National Health System** to partially settle a historical debt and thus introduce the voice of people with mental health problems in the forum where the main recommendations for mental health care and intervention were being decided.

The Committee took an active part in the campaign of the Confederation **against the proposed reform of the penal code**, contributing ideas and strategies for its design and development since 2013 and stating its own reasons against this reform in addition to collaborating in the preparation of the brochure "*10 reasons against the reform of the Penal Code in the matter of mental health*" and in the video "*We are not devoid of reasons*"^[10]. This campaign culminated in January 2015, when it was decided in Congress to withdraw from the Draft Law to amend the Penal Code all those references to security measures of an 'indefinite' nature that were intended to apply to people with mental disorders.

In addition to writing and reading the manifestos for World Mental Health Day since 2013, the Committee has also advised the Confederation, among other matters, on the approach and contents of projects implemented by MENTAL HEALTH SPAIN aimed at promoting social participation, the empowerment and recognition of rights and on the elements that should be included in the therapeutic plans for people with mental health problems.

Together with the activities that the Committee carries out as an advisory group, its members have collaborated in the preparation of the Partisam Guide, have acted as facilitators and trainers in different training programs of the Confederation, since 2014 they attend meetings of the Board of Directors and are part of the Consultative Council of the Confederation created in 2015.

3. The autonomous Committees

The development and establishment of committees in the different autonomous communities is a firm commitment of the current governing bodies of the Confederation for the direct, full and active participation of people with mental health problems, which also allows the strengthening of local networks and the associative movement.

For MENTAL HEALTH SPAIN it is very important to generate structures that serve as an example and model to help demystify mental disorders and fight against stigma. That is why the Confederation has been encouraging entities to create their own committees, with the aim of achieving a representative and direct structure of the specific interests of people with mental health problems.

Through the program "**Promotion of Mental Health and Prevention of Exclusion**" , funded by the Ministry of Health, Social Services and Equality since 2013, it has been possible to consolidate the creation of these Committees. This, together with the commitment of all the autonomous entities, has facilitated the fact that currently 84% of them already have their own Committee of people with their own experience in mental health.

4. Future outlook

For the current governing bodies of MENTAL HEALTH SPAIN, asserting the right to participation of people with mental health problems is a strategic priority of the utmost importance that is naturally linked to the defence of human rights and that today has become a fundamental guarantee for the adequate development and sustainability of the associative movement in the field of mental health.

In this sense, the members of the State Committee usually act as spokespersons to the media, participate in conferences and round tables around the country and channel and boost the information and exchange of experiences from and to the regional entities and the state confederation.

The governing bodies will continue to promote their participation in the activities of the Confederation on the understanding that the Committee is a vital tool of great importance for MENTAL HEALTH SPAIN to fulfil the mission that the associative movement of relatives and people with mental disorder has entrusted to it and, in addition, to respond to its strategic commitment to the promotion of empowerment and achievement of objectives in matters of social and political impact.

In addition, both in the short and medium term, efforts are being made to prepare projects and plans with which to assert the right to participation and government of people with mental health problems in the associative movement and in all those decisions that affect them and with which to strengthen mutual support and the exchange of experiences and knowledge.

4. Do you want to know more about the Confederation and its Committee?

- **Read about us in MHE's website:** <https://mhe-sme.org/member-spotlight-march-2018/>

- **Go to our website:** www.consaludmental.org

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