



# Empowerment of persons affected by mental ill health and self-management of care

## A Call to Action

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GAMIAN-Europe

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# Global Alliance of Mental Illness Advocacy Networks-Europe

<https://www.gamian.eu/>

We are a patient-driven pan-European organisation, representing the interests of persons affected by mental illness and advocates for their rights.

Our main objectives are: advocacy, information and education, anti-stigma and discrimination, patients' rights, co-operation, partnerships and capacity building.

Full Membership 25 countries/53 Full member associations

<https://www.gamian.eu/members/become-member/>

# Why a Call to Action ?

- The burden of mental ill-health is huge across the EU
- There is an obvious need to address mental ill-health in the most effective way
- Empowered persons affected by mental ill-health should be seen as a resource in this respect



# Call to Action aims to

**highlight** the urgent need to stimulate the empowerment of those affected by mental ill-health

and to

**recognise** the vital role persons affected by mental ill-health can play in the management of their treatment and care, in partnership with health professionals and other care providers.

## How this Call to Action was developed

- **GAMIAN-Europe** expert workshop on empowerment and self-management of care
- **Key stakeholders** - patient organisations, health professionals organisations, carers and policy makers- involved
- **Objectives:**
  - explore the current situation in relation to the empowerment/self-management;
  - identify the barriers to empowerment and self-management;
  - come forward with recommendations to improve the situation.
- Outcome used as the basis for the Call, further elaborated by **GAMIAN-Europe**
- First draft reviewed by workshop participants.

# The overarching principle: The need for parity of esteem of mental and physical health

Parity of esteem is the principle by which mental health must be given equal priority to physical health<sup>1</sup>, also in terms of resources.

In some countries, the government requires health services to work for parity of esteem to mental and physical health. However, there are many areas where parity of esteem has not yet been realised.

For instance, in the UK, mental ill-health account for 28% of the burden of disease but only 13% of NHS spending. This lack of parity is a key element in disempowering those affected by mental ill-health.

## Parity of esteem

- Principle by which mental health must be given equal priority to physical health
- This is by no means a reality
- Lack of parity is a key element in disempowering those affected by mental ill health



# The Call addresses many stakeholders

- Policymakers
- Health care professionals
- Patients
- Carers and their organisations
- Social services
- Health insurances
- Medical schools
- Primary and secondary schools
- Research institutes
- Employers



# The recommendations

[https://www.gamian.eu/wp-content/uploads/Call-to-Action-empowerment-in-mental-health\\_Final.pdf](https://www.gamian.eu/wp-content/uploads/Call-to-Action-empowerment-in-mental-health_Final.pdf)



# Policy makers should put in place health systems which are...

- patient-centred, personalised, recovery-oriented, accessible 24/7 and geared towards patient empowerment;
- less fragmented with better coordination of services;
- aim to keep patients in the community;
- supportive of the civil rights and capacity/competence for self-management
- holistic, proactive and preventative;
- aim for the least restrictive and invasive treatment and care alternative;
- aim to build capacity of organisations: advocacy and practical support;
- include patients and their families in services development.

# Policy makers should put in place health systems which...

- recognise the role and contribution of family carers and offer support where and when needed;
- allocate appropriate resources to assure access to the most appropriate and innovative treatment and care;
- provide reassurance to individuals in the form of distance monitoring and the use of 'E' and 'M' Health;
- identify/disseminate good practice to share and develop evidence-based models and enable positive change;
- provide incentives to employers to enable people affected by mental ill health (and their carers) to either enter, participate and stay in the labour market;
- launch awareness campaigns to educate society about mental ill health and facilitate more informed views and opinions.

## Health professionals should...



- be aware of their crucial role in facilitating and stimulating empowerment, work in partnership with patients;
- treat patients with dignity, compassion and respect, working towards the highest level of shared decision making;
- maximise the autonomy of patients make use of non-invasive, non-traumatic treatments;
- involve family carers in treatment and care plans;
- recognise the potential of peer support;
- address the strengths of patients rather than focus on their limitations.

## Health professionals should...



- provision of information to patients and carers as this can contribute to health literacy. This is a crucial element in self-management of treatment and care;
- check the physical health of people affected by mental ill health and the mental health of those affected by physical health problems;
- put in place better ways of communication and cooperation;
- pay special attention to children and their mental well-being;
- ensure a seamless transition when patients move from childhood to adult mental health services;
- strive for informed consent and avoid coercion to the largest extent possible.

## Patients should...



- get better organised in order to strengthen their voice;
- provide peer support;
- learn about their condition and its management, as experts of their condition;
- be more aware of their role in managing their care and treatment;
- engage in dialogue with policymakers, health professionals and family carers;
- participate in training and educational programmes, sharing the views and experiences of patients.

## Carers should...

- advocate for recognition of their role and contribution in the care provision;
- call for better access to information regarding the condition of the patient they care for, of the basic rights and entitlements, and the treatment plan in place;
- advocate their needs for support;
- request access to training to support the daily care needs of their relatives;
- advocate the option NOT to provide care



## Social services should...

- ensure the involvement of patients and carers when deciding on what services are required;
- take a holistic approach;
- work with the other health professionals to ensure coordination and integration of care



## Health insurances should...



- ensure equal priority to physical and mental health in relation to reimbursement of the best and most appropriate treatment and care;
- recognise that prejudice plays a part in reimbursement decisions as the coverage in mental health is much less than the coverage for physical health conditions;
- address this lack of parity of esteem between physical and mental health as a matter of urgency

## Medical schools...

- ensure a holistic approach in medical (re)training and education curricula;
- aim to train health professionals to take the views of patients into account and be open to the concept of shared decision making and patient-centredness;
- involve patients in education.

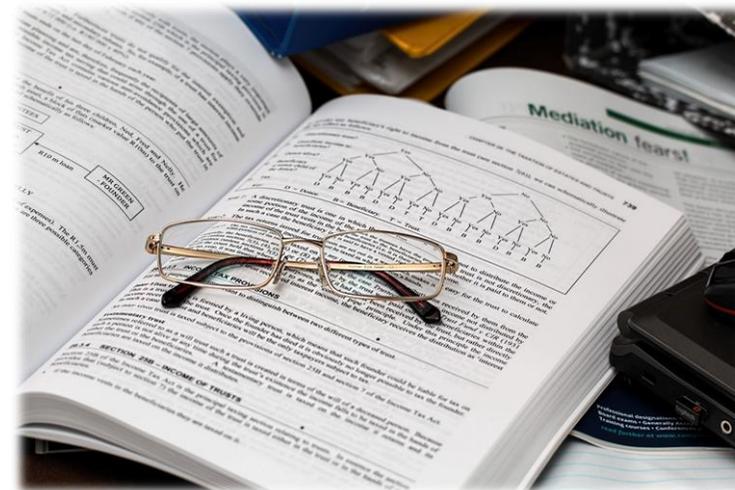


## Primary and secondary schools should...

- address mental health and encourage children to speak about their emotional problems;
- treat children as individuals and help them to find their individual strengths.



## Research institutes should...



- more dedicated research in the field of mental health;
- Include carers in mental health research;
- ensure that mental health receives the same amount of attention as physical health;
- include patients, and their family carer(s) as advisors to ensure the relevance of research;
- pay attention to the translation of research findings into (good) practice.

## Employers/social partners should..

- adapted working conditions to enable patients to enter, participate and remain in the labour market;
- address the lack of understanding as well as the lack of knowledge about how to support people in the workplace;
- share examples of good practice of what works.



# NEXT STEPS

- We will use the Call in advocacy activities, e.g. surrounding the 2019 European Parliament election



# Endorsing the Call to Action (20 June 2018):

- **EU-level organisations:**
- European Patients' Forum (EPF)
- Council of Occupational Therapists for European Countries (COTEC)
- Eurocarers
- European Brain Council (EBC)
- European Federation of Neurological Associations (EFNA)
- ADHD-Europe
- European Association for Clinical Psychologists and Psychological Treatment (EACLIPT)
- WHO Collaborating Centre
- European Psychiatric Association (EPA)
- European Multiple Sclerosis Platform (EMSP)
- European Specialist Nurses Organisations (ESNO)

## **MEPs:**

Tomas Zdechovsky (CZ)  
Nessa Childers (IRL)  
Sirpa Pietikainen (FI)  
Katerina Konecna (CZ)  
Helga Stevens (UK)  
Teresa Griffin (UK)  
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# Thank you for your attention and your **endorsement**

Please send your name and logo to me  
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