

# Families and Family Carers at the Heart of Europe



## EUFAMI Manifesto for the European Elections

In the European Union it is estimated that between 10% and 25% of the total population care for a family member affected by a long-term health condition<sup>1</sup>. Today EUFAMI represents circa 25 million families in Europe who are affected by mental ill health<sup>2</sup>, with many of those being family carers. Their work, which goes largely unrecognised, has a positive impact on their loved one's care, promoting recovery and reducing hospital admissions, non-compliance with prescribed medication, and relapses. However, families and family carers often have to deal with social prejudice, isolation and anxiety, as well as financial challenges, with many lacking the support and information that they need to care for their family member on a daily basis.

The European Parliament has a crucial role in ensuring that European families affected by mental ill health receive the support they need to fully participate in their community and share in its social, economic and political rights. EUFAMI has provided input to and welcomed the proposal for the Directive on Work-Life Balance and we call on the European Union to act in the interests of families, and in particular those families directly affected by severe mental ill health, to ensure that they are represented and supported at European and national level.

EUFAMI calls on candidate MEPs to place families at the heart of Europe by recognising the role of families and family carers and increasing the support they receive.

### Candidate MEPs can achieve this by

# 1

#### Recognising the role of the family

Family members have a central role in the care of people with mental ill health. This needs to be recognised throughout Europe, with the rights of family members provided for.

This involves:

- ✓ Recognising the unique role of families as caregivers who may themselves be in need of care.
- ✓ Enabling family members to help themselves as they care for their relative.
- ✓ Fostering respect by acknowledging the burden of care, encouraging creativity and respecting family members' personal wishes.
- ✓ Encouraging the involvement of families and family carers in recovery process discussions.
- ✓ Increasing family involvement in research, from determining priorities and defining deliverables to establishing good practices.
- ✓ Enabling family organisations to participate in health policy.
- ✓ Giving attention to the intersection of family and the economy, which will lead to better opportunities to develop meaningful solutions.

# 2

#### Helping empower families

Ensuring that the voice of the families and family carers is heard, both in terms of policy and decisions relating to treatment and care, is an important step to recognising and protecting the rights of families across Europe.

<sup>1</sup> [ec.europa.eu/social/BlobServlet?docId=19681&langId=en](http://ec.europa.eu/social/BlobServlet?docId=19681&langId=en)

<sup>2</sup> <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/data-and-resources>



Empowering families involves:

- ✓ Providing families with necessary and useful information to ensure families and family carers can contribute effectively to the recovery process.
- ✓ Giving families support based on their needs.
- ✓ Giving families a formal voice in decision-making on services provided for mental health care in the community.
- ✓ Engaging with, and involving, families.
- ✓ Reducing the risk of depression and burnout in family members.
- ✓ Providing family-centred (digital) health.

## 3

### Placing the person at the heart of mental health

People with severe mental ill health should be cared for in an appropriate environment and provided with all necessary health and social services, which is why EUFAMI is dedicated to lobbying national governments on family issues where appropriate.

Shifting the focus to the family involves:

- ✓ Acknowledging diversity: Every family is different, and family members have a right to define the role they are willing and able to play in terms of caring for, and supporting, a person with severe mental ill health needs.
- ✓ Ensuring that families and family carers have a full social life and are seen as capable contributors to society.
- ✓ Ensuring equal access to general health care.
- ✓ Implementing a legal system which ensures that those with severe mental ill health receive the treatment and support that they need.
- ✓ Encouraging and supporting the recovery processes in Europe to help provide skills, education and opportunities to people with mental ill health.
- ✓ Providing services that are aimed at the individual's needs
- ✓ Continuing deinstitutionalisation while at the same time continuing with the development of community-based care services to a sufficient extent so that families can take up their normal lives as families again.

## 4

### Advocating for the voice of families in Research

To improve the support available to families, their voice must be added to research endeavours. Promoting innovative research and ensuring that results are delivered from the perspective of families and family carers will lead to improved support for families throughout Europe. We are calling for:

- ✓ Research into the causes of mental disability and the impact it has on European families.
- ✓ Family-centred research on the effects of severe mental ill health on individuals, their families, and society as a whole.
- ✓ Research into the costs of caring.
- ✓ Research into good practices which have been implemented in European countries, with a view to adapting them and sharing them to ensure the benefits can be replicated across Europe.

## 5

### Encouraging the sharing of personal experience of mental ill health

Sharing personal experience is key to improving the support of families affected by mental ill health. By raising awareness in this way, we can highlight the positive contributions that these families make to European society as well as the impact of mental ill health on the family, and on families and family carers in particular.

This involves:

- ✓ Enabling families to communicate their own experience
- ✓ Calling for government supported peer support groups for families and ensuring that family peer workers are adequately compensated for their work
- ✓ Promoting family peer education and training
- ✓ Providing financial support for family carers and caregivers