



What perspectives for public policies in mental health?

The case of families in Europe

17 March 2016

Paris, France

Aagje leven

Secretary General, EUFAMI



The organisation

**European Federation of Associations of Families of People with Mental Illness
Europese Federatie van Verenigingen van Familieleden van de Psychisch Zieken
Fédération européenne des Associations de Familles de Malades Psychiques
Europäische Föderation von Organisationen der Angehörigen psychisch Kranker**

**Founded in 1992 – 25 year anniversary
next year**

**Represents circa 25 million families in
Europe**

**48 member organisations in 28
countries**

**EUFAMI's mission is to represent all
family members of persons affected by
severe mental health problems at
European level so that their rights and
interests are also protected and
promoted**





Research/professional expertise

+

Users' rights

+

Family carers' needs

=

Policy demands



What do families say?

#C4Csurvey with Lucas KULeuven – voices of 1111 carers of a family member with severe mental health problems throughout Europe

Full results:

www.caringformentalhealth.org

France:

www.caringformentalhealth.org/region/france



Families need support

Caregivers were **equally satisfied** and **dissatisfied** with the **support from healthcare professionals** nevertheless:

4 in **10** are dissatisfied with support from doctors

A **1/3** are dissatisfied with support from nurses

And only **3** in **10** were satisfied with support from their social workers

Half are dissatisfied with the ability to seek help and support from professional staff for their own needs

1 in **4** is dissatisfied with the support they receive from their workspace

Caregivers were more satisfied with the support from patient/caregiver organisations (**6** out of **10**)

Caregivers **don't feel involved** in **important decisions**

Only **1/3** are satisfied with their involvement in important decisions in treatment and care planning

4 in **10** are dissatisfied with their involvement and ability to influence important decisions



Less than **4** in **10** carers feel that medical and care staff take them seriously

Fewer than **1** in **4** feel communication between healthcare professionals is going well

Families need information and education

Further **essential information** is critical





Relevant EU policies

- Health – Joint Action – MH compass
 - Otherwise focus is on chronic disease
 - **Transition from institutional to community based care** – enshrined in ESIF provisions
 - **EU signatory to UNCRPD** – review Disability strategy
 - **Working carers** from perspective of gender equality
-



Relevant EU policies

- MFF midterm financial review
- **EU 2020, semester process**, country specific recommendations: austerity, demographic change and long term care
- Social pillar – AAA rating
- Refugee policy!



Research/professional expertise

+

Users' rights

+

Family carers' needs

=

Policy demands



An example

Community based care can be cheaper but it should not be promoted as cost cutting measure. We are doing this because:

- Research shows it gains better results
- Service users have a right to be included in the community

- Also right to quality care and choice



Caring for family member should always be a choice, not an obligation or a necessity, for users and for families.

Quality care in the community includes:

- Support to families, incl resources (choice), leave arrangements,...
- Inclusion of families in care decisions,
- Information and education for families



What can professionals do?

Support: Ask family carers about their needs, without support their mental & physical health will suffer

Include: Family members can be part of the solution, can be key to recovery - take their opinions seriously and include them in care decisions as much as possible

Inform: better communication is key



What can policy makers do?

Support:

- With resources, flexible leave arrangements, respite care, recognition of position of carers, protection of social security rights

Involve:

- Inclusion of users and families in decisionmaking processes

Inform & educate: invest in carers education



What can Europe do?

eg Working Carer's initiative: followup
maternity leave directive - Legal base?
Subsidiarity?

It can be done: example of Alzheimer - pressure
from NGOs and a powerful Member State
(France) led to a set of Council conclusions
mandating the Commission to take action

Coordinated pressure – role of civil society



Support families

Recognize & involve families

Inform & educate families



Thank you