



***The Impact of the UN Convention on the Rights of
Persons with Disabilities (CRPD) on Mental Health
Policies, Research and Care***

The Families' and Carers' Perspective

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Faculty Disclosure

<input checked="" type="checkbox"/>	No, nothing to disclose
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EUFAMI

1992

The birth of EUFAMI based on the principles of the De Haan Manifesto. The statutes were approved and signed by 17 associations from 10 European countries during a founding meeting in Overijse, Belgium



**Today
EUFAMI represents circa 25 million
families in Europe**

**37 member organisations in 23
countries**

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

**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**



Profile

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- Members are national or regional family associations as well as mental health associations
 - Federation of 31 family associations and 6 other mental health associations
 - Members in 23 countries
 - Members in 19 countries of the EU28
 - EUFAMI operates at the European level collaborating with bodies such the EU, WHO, professional representative bodies and like minded NGOs in the mental health area
 - Congresses are held every four years and these have been major successes – Stockholm, Barcelona, Colchester, Torun, Basel, Sofia ... and coming in 2019 Helsinki ...
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Focus of work

EUFAMI's work and activities is specifically focused in:

- Community Care and the impact on families
- Economic situation and its impact on families
- Promotion of the essential role of the family in care
- Prevention of mental ill health and how research can be used to improve the situation
- Social inclusion
- Recovery
- Health issues facing the family carer
- Impact of Depression
- Youth and Mental Ill health



EUFAMI has long been advocating for

- Transition to community care
- A stronger focus on the rights and well-being of patients/service users
- Further change needed, based on concerns and needs raised by people with self-experience

Typical scenario: at the usual age of onset of a child's mental illness, the age of family carers, generally between 40 and 60, means they are at a time of greatest family stress and pressure.

**Mental illness develops
in older teenager or
young adult**

age: 15 20 25 30 35

Provide
special
care at
onset

Provide
continuing
support

**Family carer's
commitments and
responsibilities**

age: 40 45 50 55 60

Work career reaching peak

Pre-retirement

**Other children
in family**

Provide
support
at school
or college

Provide
support
at time of
grandparents'
retirement

Provide
increasing
care and
support

Grandparents

age: 65 70 75 80 85



Family care is an integral and essential part of mental care, particularly in a community based system of care.

Family carers and informal carers are the invisible workforce that bring enormous value to society in the form of better outcomes for the people they care for



The needs of families and family carers are often overlooked when the services landscape is being designed.

This weakens the entire system of community based care



Caring for carers



CARING FOR CARERS SURVEY (C4C)

Experiences of family caregivers of persons with severe mental illness: **An international exploration.**

The aim of the Caring for Carers (C4C) survey was to assess the experiences of family caregivers in caring for their relative with severe mental illness from an international perspective, and to highlight the central role they play. The C4C survey was undertaken in 22 countries and received over 1,000 responses, the majority (64%) of which were from those caring for people with schizophrenia/psychosis.

Respect for patient's rights, but also for
carer's needs.



The expertise of Families

- Family caregivers have special knowledge and experience to contribute to the whole process of diagnosis, treatment, care and recovery of the patient/ service user
 - At the diagnostic stage families are usually the first to notice the possible warning signs and have essential relevant information to communicate
 - They also become the main, if not sole source, of the care provided - ***often full time***
 - The transfer of care and treatment from hospital to community settings significantly expands this role and creates extra pressure on families
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The **worry** and **stress** means that

1 in **5** feel so exhausted that they cannot function properly

1/3

lack sleep because of the worry
and stress



1/3

feel
depressed



1 in **5**

are unable to find anything
positive in their life



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



Around **9** in **10** want **more opportunities to meet** and share knowledge and experiences with:



Professional carers

93%

As well as with other family
members and informal carers

90%

4. CRITICAL SUPPORT FOR CAREGIVERS - **WHAT THEY ARE TELLING US THEY NEED**

A **staggering 93%** would appreciate some additional support in their role as caregiver

With nearly **half** requesting a significant amount of additional support

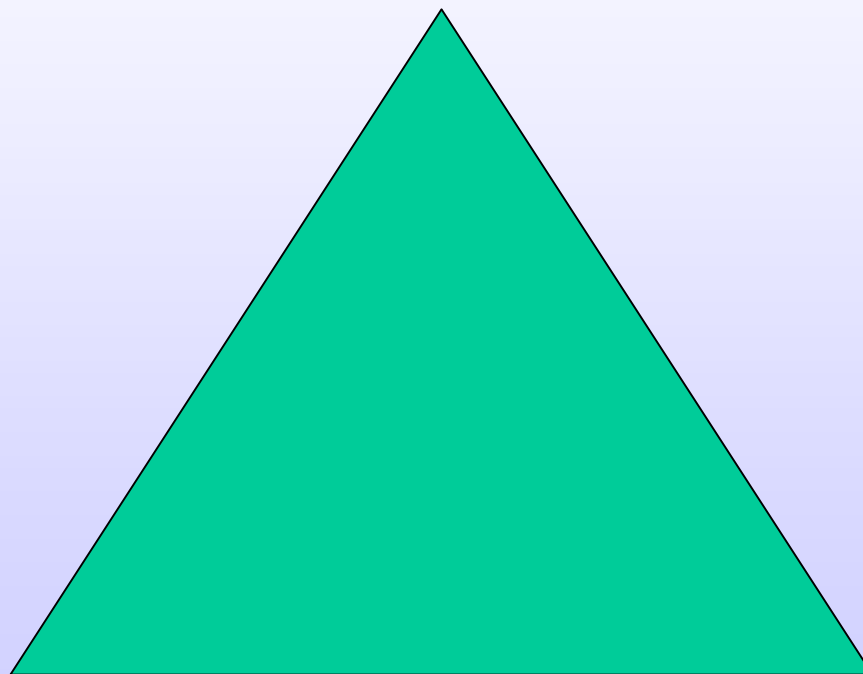


Only **7%** need no additional support

TRIALOGUE

Open communication and mutual understanding

Persons with self experience



Medical Professionals

Families and Friends

The greatest need of family carers lies in the recognition that they are a full partner in care and in the need to be listened to and taken seriously by the medical and other professions.



Policies in mental health should offer family members a choice to care or not to care

- Deinstitutionalisation accompanied by investment in local support services, including for family members
- Flexible working hours, financial & other support measures so it is possible to choose to be a working carer – (for which EUFAMI looks to the EU)



Family carers who choose to care need to be supported in that choice through education, financial and emotional support, peer support groups, etc.



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



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

8 out of 10 want **individual support** from **EUFAMI** and family member organisations by providing/offering:



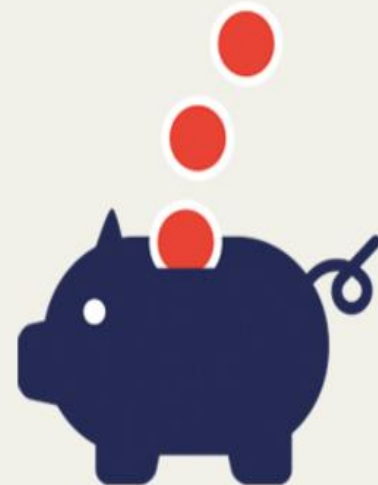
Information
88%



Emotional support
83%



Respite care
78%



Financial support
62%

Reduce stigma in general – key issue for families as well as people affected by mental ill health.

Stigma

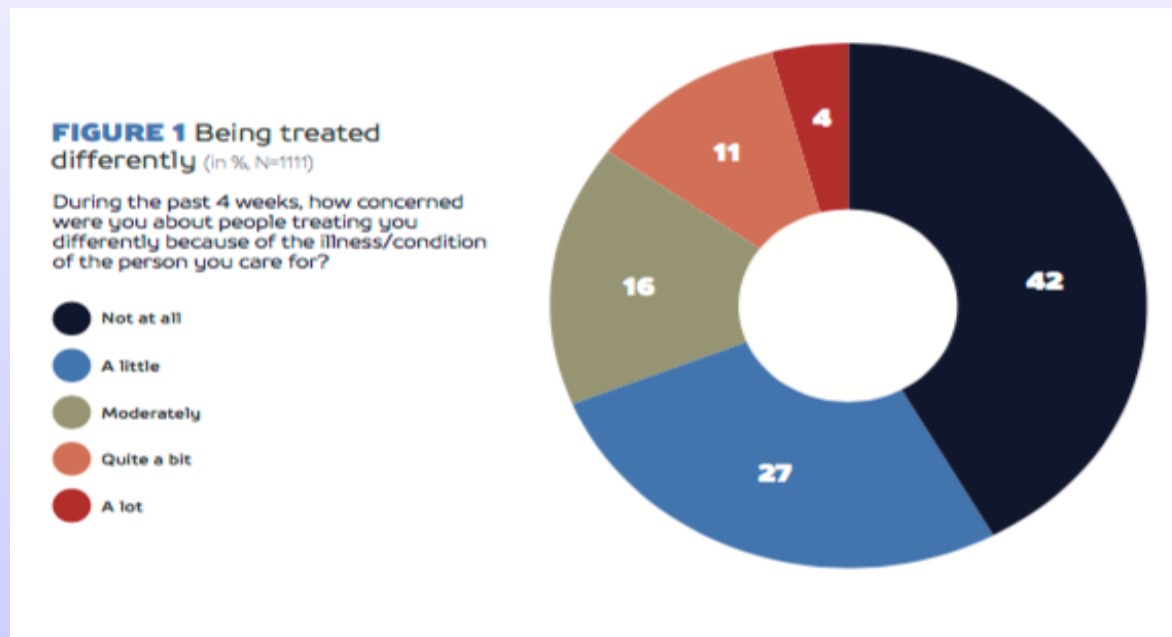
- The stigma surrounding mental ill health is strong in our community.
- **Stigma affects not only those with mental ill health, but also their families and carers as well**

“I now feel it is all my fault that my daughter is the way she is. I could see the neighbours treating me differently. Turning their heads, becoming occupied when I approached. It has gotten so bad that I only go out at night, when there is non one around.”

Jean (mother of Ann, 26, student with severe mental illness)

Perception of stigma among carers

- One third report feeling that they are treated differently because of the mental illness of the person they care for (C4C survey)



Family caregivers have typically cared for their loved one for **15** years.

Caring can also involve **positive experiences** with more than **half** of caregivers discovering **inner strength**.



More than **1 in 3** family caregivers are at the **point of reaching breaking point**.

4 in 10 feels **unable to cope** with the **constant anxiety** of caring and experience these feelings "quite a lot" or "sometimes"

1. THE HIGHS AND LOWS OF CARING

Family caregiving for people with severe mental illness involves feelings of **stigma and burden**, however, these experiences can be coupled with **positive caregiving experiences**.





Thank you