



Destigmatisation and Improving the Quality of Care in Psychiatry

How Families and Carers are playing their part to help improve the Quality of Care

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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

Provide support at school or college

Provide support at time of grandparents' retirement

Provide increasing care and support

Other children in family

Grandparents

age: **65** **70** **75** **80** **85**



Background

- Families and Carers
 - They had a task to do – caring for their ill relative
 - Traditionally remained in the background
 - Many felt ignored and undervalued
 - Accepted their situation and faced up to the challenges
 - No Communication with medical team
 - Got on with the task
 - Silent Partners

But then, some progressive thinking carers realised....



Realisation (Awareness)

- Carers had their own needs which required attention
- Formed local self help groups –
 - Later – regional and national groups
- The next step was to organise at European level
 - They had something valuable to contribute
 - A constructive role to play
- And so, EUFAMI was founded



Introducing EUFAMI

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
- Represents millions of families in Europe
- 48 member organisations in 28 countries
- Based in Leuven, Belgium





Central aims of EUFAMI

- ***Promote and ensure continuous improvement of quality of care and welfare for people affected by mental illness throughout Europe***
- Increase level of support for families and carers
- Strengthen and support member associations to improve local mental health conditions
- ***Influence government policy related to mental illness/health***
- Work together on all levels by enabling member associations to act jointly on the European level
- ***Cooperate with health professionals, patient organisations and other stakeholders***



Approach to achieve aims

How?

- Focused engagement programme

With whom?

- Legislators and Policymakers
- Key Influencers
- Care Team - Professional Bodies
- Media
- Other Advocacy Groups
- Own members



Pre Requisite - Empowerment

- Family members and carers play an important role. Their contributions must be acknowledged appropriately
- Carers should have the right and opportunity to state their needs
- They should be allowed to define the role they are willing and able to play
- Carers should be provided with quality information in their own language

But how can these objectives be achieved?

*One way is to **empower** family members*



PROSPECT – A path to Empowerment

Peer to Peer training method “PROSPECT” developed by EUFAMI





STIGMA

Society has a 'lock them up and throw away the key' attitude to mental illness. The social stigma must be dealt with.

zerostigma

EUFAMI's Zero Stigma campaign is working throughout Europe to change attitudes and behaviour towards people with a mental health problem, and to replace prejudice, ignorance and fear with acceptance, knowledge and understanding.





Contribution to Policy making

- Early Engagement - essential
- Partnership – best approach
 - Not viewed as combatants
 - Better resulting legislation
- United voice
- Strength and power



Some Recent Examples

- WHO Ministerial Conference, Helsinki
 - January 2005
 - Good relations with the WHO
 - Families and carers recognised
- EU Commission's Green Paper/Pact for Mental Health and Well-being
 - EUFAMI part of working group
 - Submitted consensus response and other contributions
 - Continue to be an active participant
- EU/WHO Empowerment project



Cooperation with other Advocacy Groups

Why?

- Common aims
- Strength in a United Voice

Who (example)

- European Disability Forum (EDF)
- European Patient Forum (EPF)
- Mental Health Europe (MHE)
- European Network of (ex-)Users and Survivors of Psychiatry (ENUSP)
- Global Alliance of Mental Illness Advocacy Networks – Europe (Gamian Europe)



The Media

Why?

- Major influencers in public attitude by how they report Mental Health related issues

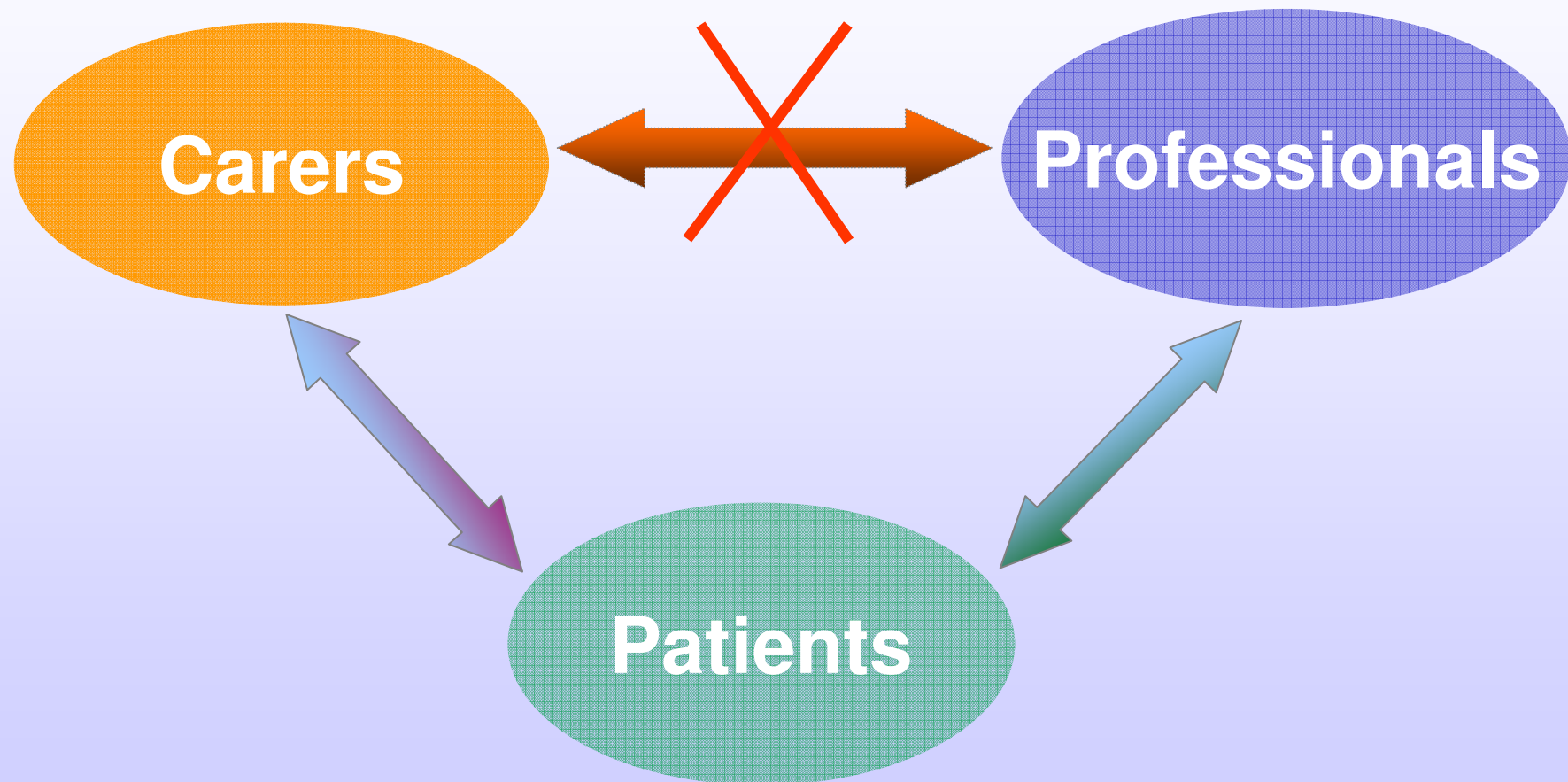
Objective

- More accurate, responsible and positive reporting

How?

- Proactive engagement with media
- Lexicon
- Local Monitoring Service – example Headline

The communication gap – the challenge





Triialogue – a path to better communications

- Professionals understand their principal responsibility – patient
 - Difficulty in communicating with families
- Need to break down barriers
- Engage in a united front
 - More to learn
 - Family support is necessary
 - Families also need help
- Unity can help in achieving policy changes



The person – a new approach to Training

- Healthcare services should reflect the needs and priorities of patients
- Growing emphasis on involving patients and caregivers
- Power imbalance between providers and patients/families
- Changing role of the patient
- Recognition that patients/ carers can contribute to education & training
- Developments in academia, curriculum changes
- User and Carer movements
- Good practice care
- Health care reform
- Improved Outcomes



Training - ways to involve families

- Decision making
- Managing
- Planning
- Teaching
- Assessing
- Reviewing
- Evaluating



Families and carers

- Extensive Network (valuable resource)
 - Self development work
 - Research
 - Surveys
 - Dissemination and Exchange resource
 - Development of patient and carer material
 - Advisory Boards



Family involvement to date – some examples

- Carers recognised as having a legitimate voice
- Acknowledged as a credible source of knowledge and expertise
- Families fully participate in contributing to policy making, WHO Helsinki meeting, EU Health Process
- Full involvement in the Consultation process for the EU Commission's Green Paper
- Participating on a number of Advisory Boards
- Full consultation with medical professional bodies
- Recognised as having a significant role to play in the formation and delivery of MH services



How EUFAMI (Families and Carers) is contributing and playing its part

- Engagement with Policy Makers
 - Contribute comments, suggestions, idea, views
- Knowledge transfer
 - Share experiences and outcomes – Trialogue, Prospect
- Engage with professional bodies
 - European and National level
- Contribute to Training Standards
 - Join Standards Working Party

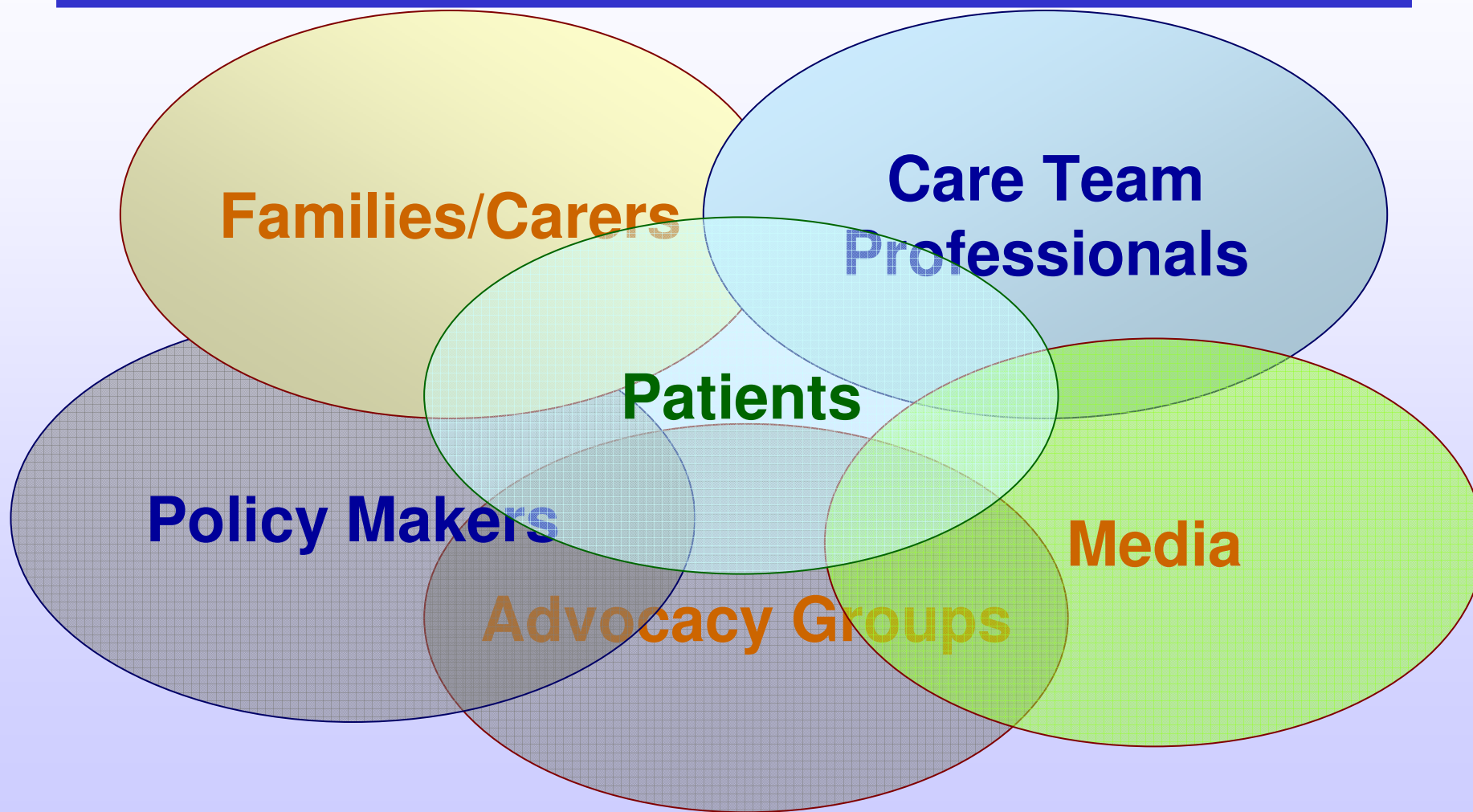


How can EUFAMI contribute (continued)

- Prospect
 - Recognition and Adoption of Professional Module as part of Training
- Use of EUFAMI extensive network
 - Dissemination of Information and Data gathering
 - Research
- Result
 - Better and easier life for all concerned
 - Improved cooperation/partnership
 - Better understanding by overcoming 'language' barriers



UNITED - Health system stakeholders





THANK YOU