

IDOP 2008: GLOBAL PERSPECTIVES ON FAMILY CARE **United Nations Headquarters, New York, NY, 1 Oct 2008**

Carers Organisations in Europe

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EUROFAMCARE

European study on family care for older people

- Main background for my presentation:
 - study on the situation of family care on **older** people in Europe – **EUROFAMCARE***.

- Two main parts:
 - **Background reports from 23 European countries** and a synthesis report (secondary analysis)
 - **In-depth Six-Country-Survey** (interviews with 1,000 family carers per country)

*Funded by the European Union from 2003 – 2005;
co-ordinated by Hanneli Döhner, University of Hamburg



EUROFAMCARE – Importance of family care for dependent people

- Due to demographic factors and developments in medical care and social support an increasing number of **people require long term care** (paradigma change from acute to LTC).
- In European countries about **80%** of this care is provided by **informal carers**, mainly women (spouses, daughters, daughters-in-law, other relatives, friends, neighbours).
- In nearly all European countries the family is regarded as the **main responsible institution** of elderly care.
- Without the work of these unpaid carers, care systems would be totally **unsustainable** and many acute needs would remain unattended.

EUROFAMCARE - Burden of family carers

- Carers more often give **positive statements** about their caring experience than negative statements.
- We found **high willingness to care**, although the following **negative aspects** are reality. Family carers:
 - are not well informed
 - are overburdened
 - have a high risk to fall ill oneself
 - have difficulties in combining care and paid work
 - have a loss of income
 - have the feeling to be on one's own
 - do not feel appreciated in their care work
 - have a high risk for physical, psychological, sexual, financial abuse and neglect (often hidden)

EUROFAMCARE - Service use and need

- But more than three quarters of the carers **never used specific support services.**
- If services are available and used, however, **satisfaction is high.**
- Despite efforts made so far, **information and advice** (esp. on diseases, availability and access of support services) - considered as the most important offer for family carers in all countries - is still a problem.

EUROFAMCARE – Aims for further developments (1)

Against this background the project EUROFAMCARE aimed

- to highlight **differences** in the situations, circumstances and needs of family carers within and between European countries.
- to ensure that the valuable work of family care for older people receives **more recognition** and will be on the **political agenda** in all European countries,
- to give more awareness to the urgent need of **innovative legal answers** to the increasing need for long-term care and the gap in adequate services – realising that more and more families decide for **migrant** home care workers (mostly cheaper, quality is under discussion - often irregular workers).

EUROFAMCARE – Aims for further developments (2)

Consequently, based on the research results, EUROFAMCARE members were contributing to several initiatives including a

- European **Network for Carers**
- European **Carers Association**
- European **Carers Charter**
- European **Carers Day**

Need for a Carers Lobby

- There were only some European countries with a longer **tradition of national carers organisations**, but there was no European Carers Association.
- Based on the initiative of another EU funded project – CARMEN - together with EUROFAMCARE, representatives from carers' organisations and research and development groups from **eight countries** met in **2004** to establish a European-wide organisation to represent and provide a voice for carers

EUROCARERS – European Association Working for Carers

(President: Baroness Jill Pitkeathley)



EUROCARERS – Definition of carers

- **EUROCARERS** defines a carer as a person
 - who provides unpaid care
 - for someone with a chronic illness, disability or other long lasting health or care need
 - outside a professional or formal framework

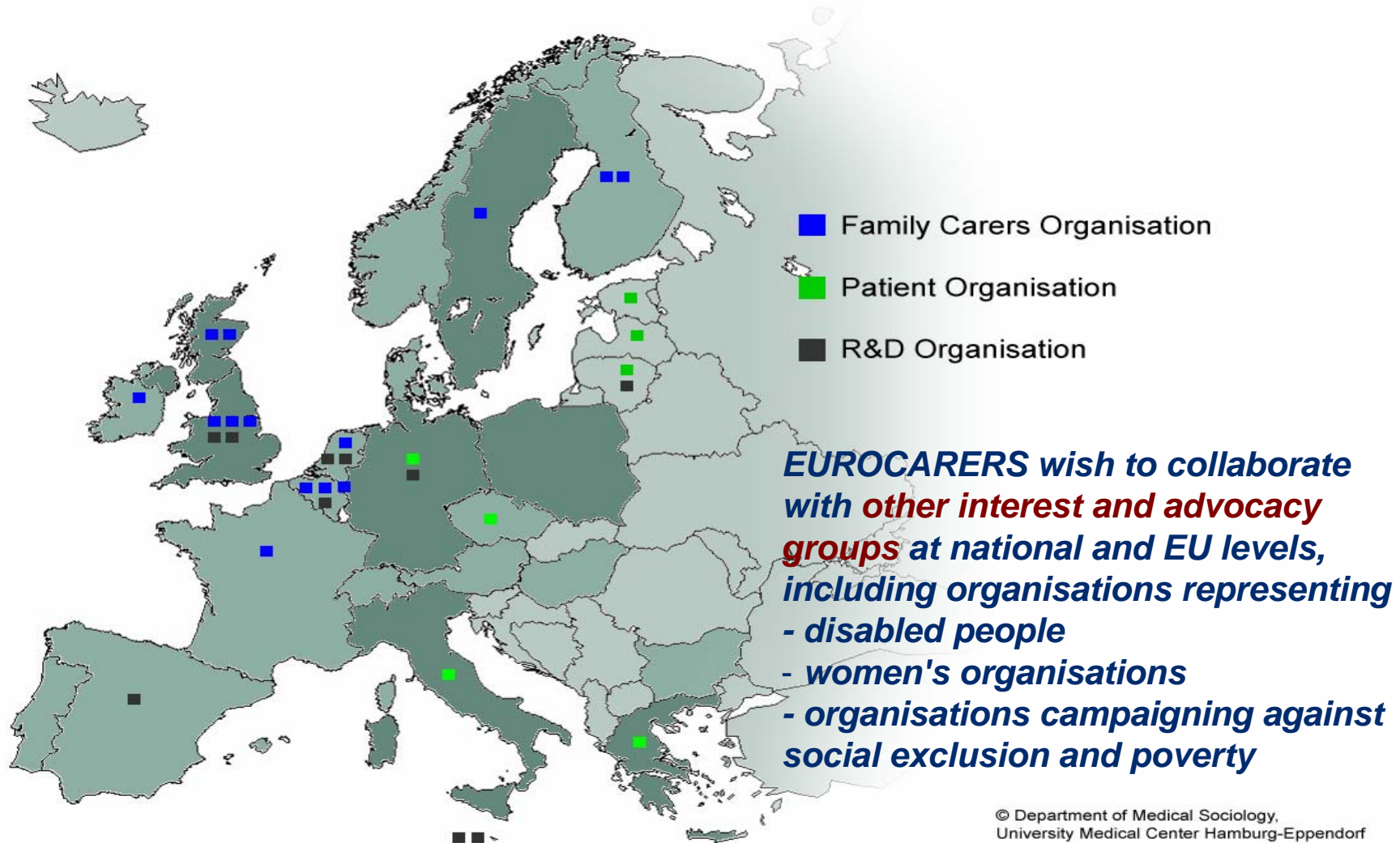
EUROCARERS - Aims

- EUROCARERS aims to advance the issue of informal care by:
- Supporting the **development** of carers organisations
 - Providing a **united voice** at European level
 - Influencing policy at **national** and **EU** levels
 - Promoting **awareness** of carers issues
 - Disseminating experiences and **good practice**
 - Providing information on relevant EU **policy** developments
 - Developing an informed **research** agenda

EUROCARERS - Funding

- **Membership fees** only can not guarantee the sustainability of the association.
- In the first years: mainly by the **EU** realised by the involvement of Carers UK in a European Program
- In the last year: a EU proposal for further development of the association not successful
- This year a new approach to the EU is intended
- In summary: The fight for funding is a main activity of the board as a prerequisite to reach the mentioned goals in the future.

EUROCARERS – 31 Members



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EUROCARERS - 10 Guiding Principles as a background for further action

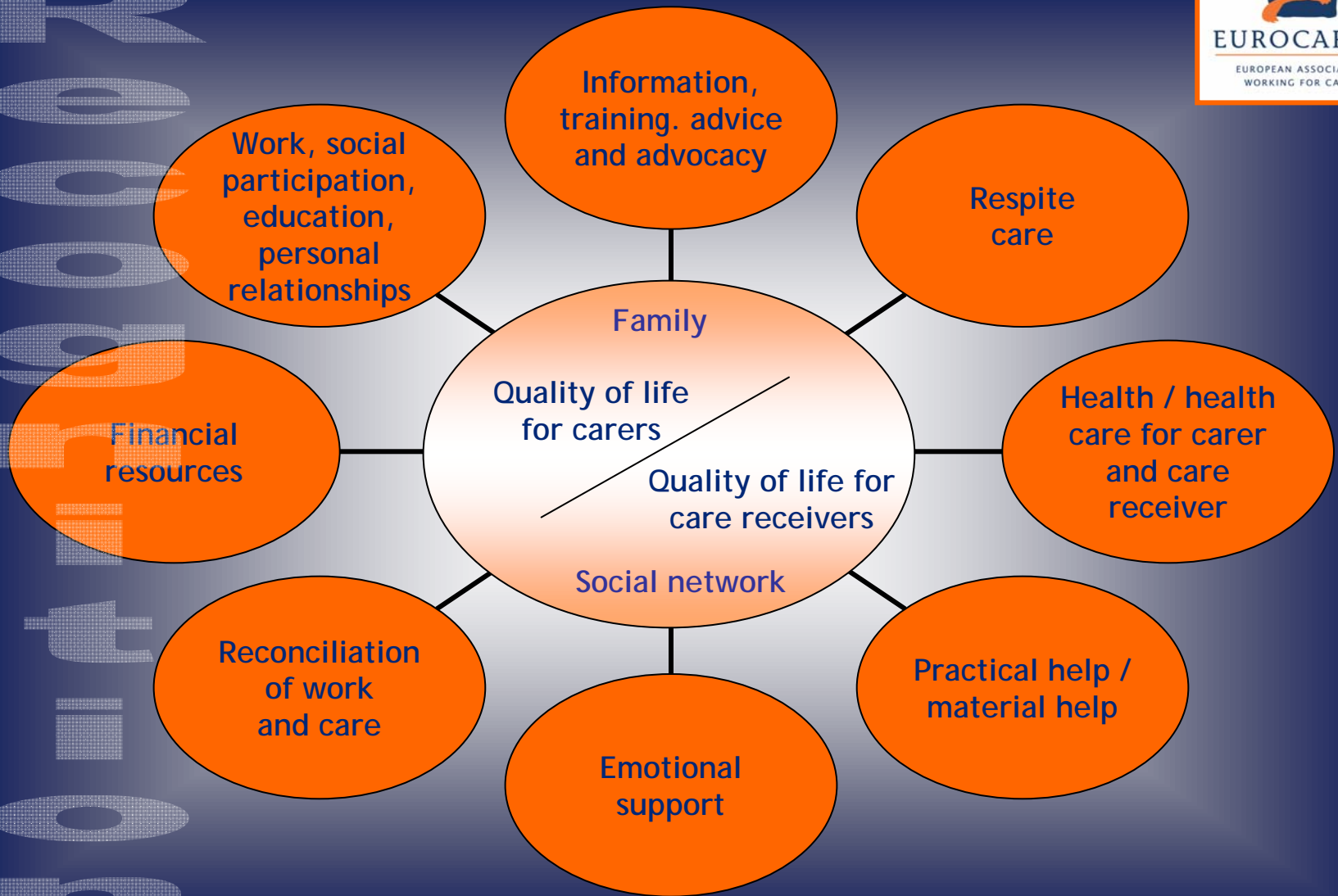
- Principle 1: Recognition
- Principle 2: Social Inclusion
- Principle 3: Equality of opportunity
- Principle 4: Choice
- Principle 5: Information
- Principle 6: Support
- Principle 7: Time off
- Principle 8: Compatibility of care and employment
- Principle 9: Health promotion and protection
- Principle 10: Financial security

EUROCARERS - 10 Guiding Principles

These guiding principles

- give **direction** to further activities and priorities
- are **suggestions** for new **national** carers organisations
- should therefore be **translated** in different languages
- are the driving topics for EUROCARER's **research** programme. Consequently a **framework for quality outcomes** for carers has been developed that will be presented in the IAG World Conference in Paris 2009.

Quality Outcomes for Carers: EUROCARERS' Framework



Lessons to learn from countries that have already carers organisations

Based on a short questionnaire concerning European **national carers organisations**, we found that

- issues of family members get more awareness and
- there is a strong **political influence** of national / regional representation of interests regarding e.g.:
 - financial support and technological assistance
 - range of services to support carers all over the country
 - better compatibility of care and paid employment
 - regarding carers as a target group for health promotion, prevention and treatment

Development of a German Carers Association – Steps in 2007 - 2008

1. Spring 2007: **Proactive groups** with representatives of self-help, consulting services for family members, politics, social insurance and sciences made first plans
2. Fall 2007: **Workshop with 30 family carers** from all over Germany
3. Spring 2008: **Official establishment** of the new German carers association

Wir pflegen – Interessenvertretung begleitender Angehöriger und Freunde in Deutschland

We care – voice of caring families and friends in Germany

German Carers Association – Challenges for the development of carers organisations

- Voluntary work essential - till funding might be available
- Potential conflicts between members that are carers and professionals
- Believe in fighting for the same interests
- Acceptance of different backgrounds and motivations
- Different ideas of the speed for developments
- Transparency of the work of the board for the members
- Decision making process for common statements
- **Patience – patience – patience and funding**
... to reach the goals

Carers are the backbone of LTC worldwide

- Long-term care will only be **sustainable** when carers will get more support early enough – before getting ill themselves!
- The **economic value** of care-giving is enormous.
 - As an example: fictional earnings for carers in NL are twice the figure spent on professional nursing and caring.
- Nearly **all of us** will be a carer at some time in our life course – for a shorter or longer period
- Carers' organisations have to convince political decision makers to give **adequate awareness** to family carers value for societies!

Would a

Day for Carers all over the world

be a promising investment?

Thank you for your attention!

More information:

EUROFAMCARE

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EUROCARERS

EUROPEAN ASSOCIATION
WORKING FOR CARERS

**EUROCARERS – European
Association Working for Carers**

www.eurocarers.org

EUROCARERS is registered in Luxembourg in
2006 under no F6854

EUROCARERS – Members (1)

Carers´ associations:

1. Carers UK
2. The Coalition of Carers Scotland
3. Caring for Carers, Ireland
4. Care Alliance Ireland
5. Finnish Carers´ association
6. Finnish Network For Organisations Supporting Family Caring
7. Mezzo, Dutch carer´s association
8. Aidants, French carer´s association
9. Swedish carer´s association
10. Flemish carers´ association, Belgium
11. Belgian Carers Association

EUROCARERS – Members (2)

Patients' associations:

1. Athens Assoc. Alzheimer's Disease, Greece
2. Workgroup Homecare, Belgium
3. Czech Alzheimer Society
4. Estonian Multiple Sclerosis Association
5. BIVA, Germany
6. AIMA – Italians Alzheimer's Association
7. Latvian MS Association
8. Lithuanian MS Union
9. The Institute of Family Relations, Lithuania
10. SOS – Solidarity Overseas Development Malta
11. CA – Contact a Family, UK
12. Crossroads Association, UK

EUROCARERS – Members (3)

R&D-organisations:

1. MOVISIE - Center of Expertise for Informal Care, NL
2. VILANS, NL
3. Free University, Hamburg, Germany
4. Social Policy Research Unit, University of York, UK
5. CIRCLE, University of Leeds, UK
6. University of Antwerp, Belgium
7. SEAS, Spain
8. MAGG - Maltese Association of Gerontology and Geriatrics

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