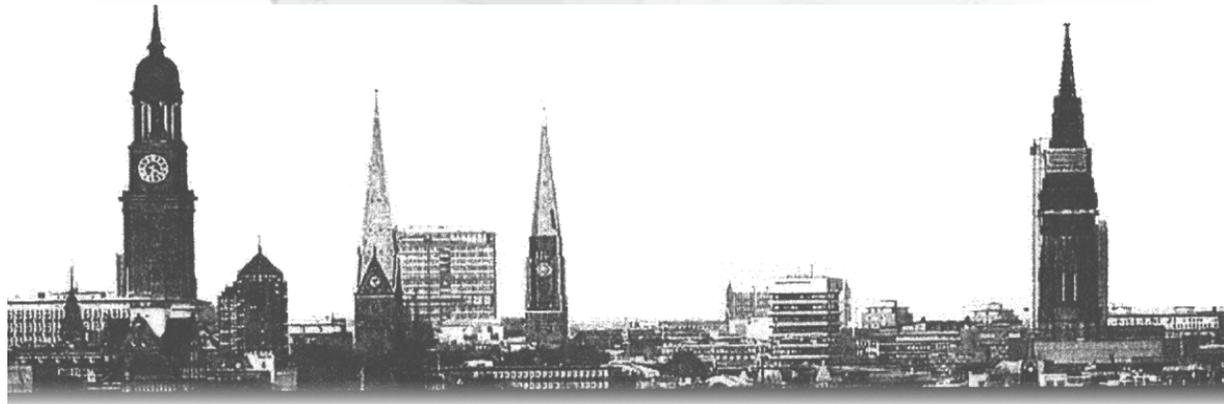


Welcome to Hamburg!

EUROFAMCARE Final Conference
Hamburg 18th of November 2005

Family Care of Older People in Europe





The 5th Framework Programme: Quality of Life and Management of Living Resources

Services for Supporting Family Carers of Elderly People in Europe:

Characteristics, Coverage and Usage

EUR FAM CARE E

Key Action 6: The Ageing Population and Disabilities 6.5: Health and Social Care Services to older People

This project (Contract: QLK6-CT-2002-02647) is supported by the European Union in the Vth Framework Programme:
Quality of Life and Management of Living Resources - Key action 6: The Ageing Population and Disabilities
6.5: Health and Social Care Services to Older People





EUROFAMCARE

Consortium

National Advisory Groups

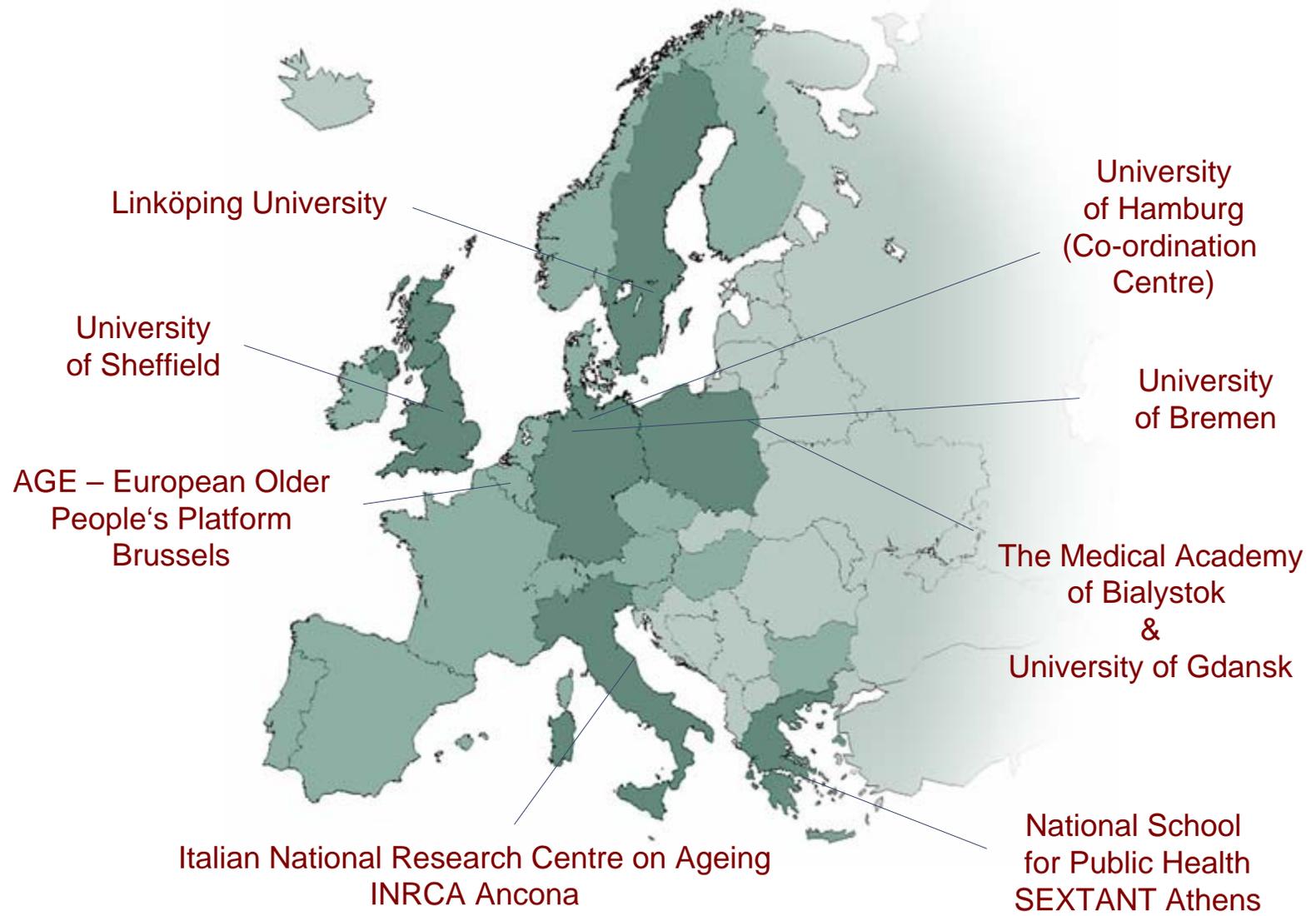


Core Group



Pan-European Network

International Advisory Board





Family care in Europe: Issues and challenges A view from the literature

Mike Nolan



Research, policy and practice: some disjunctures

- Family (informal) care has been a 'major focus of study for at least 20 years' (Pearlin et al 2001)
- Resultant 'voluminous literature' (Fortinsky 2001)
- Nevertheless there remain several 'unresolved issues' (Pearlin et al 2001)
- 'After a long period of disregard, informal carers are now fully recognised as the bedrock of care for older people' (Kröger 2001)
- A major policy goal is to 'support family carers and strengthen the integration between formal and informal systems of care' (Banks 2004)
- BUT policy varies widely, and often considerable gaps between policy rhetoric and reality of practice on the ground
- What is required is a 'well balanced dialogue' (Nies 2004)





Some fundamental questions

- 'With its strategic importance and the unresolved issues supporting it, we expect that the family will continue to be centre stage for many years to come' (Pearlin et al 2001)
 - **What** are the 'unresolved issues'?
 - **Why** support family carers?
 - **Who** to support?
 - **What** do we mean by carer support?
 - **When** is support best provided?
 - **How** is support delivered?

- Developing better carer support



Why support family carers?

Not an issue in several countries as no formal acknowledgement of family care either due to:

- a) Taken as read role of the family
- b) Taken as read role of the state

BUT changing

In countries where family care is acknowledged, the implicit motivation in most is instrumental either to:

- a) Ensure a supply of future carers
- b) Maintain existing carers in their role





Towards a rights based approach

Recent work by the Scottish Executive promotes:

- 'Bold new vision'
- People first and 'unpaid carers' second
- Adopting a caring role should be a 'positive life choice'
- Unpaid carers as key partners and providers
- Rights based policy framework
- Expert carers, expert carers programmes
- Paradigm shift in culture and practice





Who to support?

- Older person with potential benefit to the carer
- Carer themselves
- Both/wider family
- Dyadic/triadic models
- Reconceptualisation of the 'place' of carers, with a move away from resources per se to 'partners'
- Implications of this shift for the relationships between family and professionals, and the role of professionals and their training
- Who provides support – family/friends, self-purchased, voluntary, state and the balance between these





What do we mean by carer support?

- Range of support potentially available but often narrowly conceptualised
- Most underpinned by a stress burden model
- ‘Major tenet of gerontological policy and practice’ (Zarit et al 1999)
- May have restricted service innovation (Quereshi et al 2000)
- Meta-analysis of interventions (Sörenson et al 2002)
- Out of 78 studies – 57 burden, 40 depression, 3 uplifts/satisfactions
- Very little attention to strengths-based models (Berg-Weger et al 2001)





Towards a broader conceptualisation

- Askham (1997): Any intervention that helps carers, or potential carers, to:
 - take up, or decide not to take up, a caring role
 - continue in a caregiving role
 - end a caregiving role
- Major focus of attention currently is on ‘continuing’ in the caregiving role
- Most services/support are reactive rather than proactive
- Considerable gaps – young carers, BME carers





When is support provided?

Several studies identify

- ‘threads of continuity’ (Aneshensel et al 1995) or
- ‘discern consistency’ (Montgomery and Kosloski 2000) that can act as
- ‘markers’ for appropriate support, and key decision making points

‘The form, content and timing of interventions should depend to a considerable extent on where carers are in their careers, and involve an understanding of what has passed before, and what is likely to be ahead. That is, the problems encountered today should be viewed against the backdrop of yesterday and with an eye towards tomorrow.’ (Aneshensel et al 1995)





Implications for support

- Temporal models of care can identify points at which certain types of support are needed
 - Entry to caregiving role
 - During caregiving role
 - Choosing alternatives
 - End of caregiving role
- Little account of such models taken in service design and delivery





How/where is support best provided?

- Individually
- Groups
- Face-to-face
- Remotely
- In home
- Elsewhere
- Target domain, for example, cognitive, affective, psychomotor
- Taking a pharmacological metaphor we still do not know the best route, dose or length of treatment
- Room for considerably more innovation, eg in use of ICT





Developing better support services

- 5A's – Availability/ Accessibility/
Appropriateness/ Acceptability/ Affordability
(Whittier et al 2002)
- Availability
 - Still focus on cared-for person
 - Widely divergent both within and between countries
 - Certain types almost universal – eg respite
 - Others very limited
 - Several gaps – eg young carers, BME carers





Are they accessible?

- Not just geographically/physically
- How do carers 'access' services?
- Knowledge – information often very limited
- Assessment
 - usually a form of gate-keeping
 - eligibility driven
 - little match between carers' views and those of the provider
 - often not a positive experience for the carer
 - services rarely negotiated





Appropriateness / Acceptability

- Often closely linked but, despite need, services often rejected – ‘why’?
- Carers weigh ‘costs and benefits’ of help and reject if former are greater than latter
- Need to be seen as ‘meaningful’ to carers (Schulz 2001)
- Need to be ‘connected’ with carers’ concerns and ‘congruent’ with their expectations (Wuest and Stern 2001)
- Of suitable quality
- ‘System induced setbacks’ (Hart 2001)
- Often hinge critically on the nature of personal relationships between providers and carers (Scottish Executive 2005)





What can EUROFAMCARE offer?

- Cannot answer all the above questions
- But can illuminate many of them – existence, familiarity, availability, use and acceptability of support services
- Provide important pointers for future policy, practice and research
- ‘In summary, during the past 40 years, research has only scratched the surface regarding our understanding of the caregiving experience’ (Pruchno 2000)



