Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage

EUROFAMCARE

WP 15: Research Action (REACT) Report

(including deliverables 23 and 24)

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1 Introduction

The main objective of the work package 15 – REACT – was:

- to contact a network of service providers and privileged witnesses – public and private service providers, elderly and caregivers' organisations, health and social care authorities – in order to collect and evaluate the network members' interpretations of and reactions to the survey results, especially in cases of controversial or critical aspects identified by them;
- to achieve a better understanding on the gap between perceived needs and "political reality";
- to contribute to an "active" change of attitudes amongst health and social care system actors towards the partnership approach in family care;
- to provide a manual of innovations, good practice, methods of cost effective operation, management, training etc., for public and private agencies with interest in or responsibility for the design and running of support services for family carers of older dependent people.

Originally, the starting point of WP 15 was November 2004, the completion date July 2005. There was one modification against the CPF: at the Linköping meeting the consortium did not regard the REACT-phase as a time limited component of the project. The general opinion was in favour of keeping the practice orientated element of the REACT phase open for as long as possible, at least until the end of the project. Details were discussed at the 5th meeting in Gdansk, October 28th to 30th 2004. As preparation Poland presented some ideas in Torun in September 2004. A working group was established there which finally consisted of the following people:

- Germany (Hamburg) – Hanneli Döhner, Susanne Kohler
- Greece – Judith Triantafillou and Liz Mestheneos
- Italy – Giovanni Lamura
- Poland – Beata Wojszel, Piotr Bledowski
- Sweden – Barbro Krevers
- UK – Mike Nolan and Jayne Brown

Details of the REACT Phase were discussed at the 5th meeting in Gdansk, and final settlements were established during the 6th project meeting in Sheffield, and a final meeting in Hamburg.

Time-table

REACT as a dissemination phase shall – as initially discussed in Linköping – be kept conducted as long as possible until the end of the project and longer.

Level of realization

The REACT could be realized on national, regional and local level (six countries) as well as on European level (see also AGE: WP 12).

Target groups

Family carers, service providers and policy makers

Actions planned

Contain different kinds of dissemination activities such as:

- national, regional, local workshops
- discussion groups
- interviews with chosen authorities
- publications and presentations on the local, regional and national level with participation of the service providers, NGO, local authorities as well as policy makers

Methodology

- Agenda: depending on the kind of the event
- documentation of the events

Products of the REACT (DELIVERABLES 23 & 24)

1. Guidelines for family carers

- on national level, in national language, including more practical suggestions
- the content of the document shell depend on the specific situation of the country and every partner is responsible for it's production
- no size limits

2. Guidelines for policy makers and service providers

- national level
    - in national language
    - the content of the document shell depend on the specific situation of the country and every partner is responsible for it's production
    - no size limits

- European level
    - in English language
    - the content adjusted to European data
    - AGE-platform is the partner responsible for it's production (WP 12)

As the term “guidelines” is differentially connoted in different languages, every partner will use their own terms. Products shall be developed on the basis of REACT activities (see tables below) and the NASURs on the national level and under national responsibility. This means that probably different products / versions will arise.

There was an agreement, that partners will produce an own “action plan”, on what they will do (description of activities only). The bigger content of the deliverable might follow after this year – till the end of the project. What each country does (according to the form) is under the responsibility of each partner. No size limits have been decided, but each partner gives a justification why they did the products the way they did (half a page).

Independently from the different national strategies, every partner provided a summary describing the results / recommendations for the final report. They need not to be directly comparable between countries on the basis of a common form or protocol. The content of the recommendations depend on their addressee.

In the following you will find an overview over research actions carried out by the six core countries followed by short descriptions of the actions conducted in the countries. In the annex of the report are the drafted deliverables of the countries.

2 REACT Activities

2.1 Germany

GERMANY					
Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
2005-08-10 **Hannover** (2.5 hours)	Diakonisches Werk der EKD [Organisation of the Deaconry of the Evangelic Church in Germany]	Fachtagung [Symposium]	ReferentInnen für ambulante gesundheits- und sozialpflegerische Dienste [Representatives of health and social outpatient care providers]	“Angehörigenarbeit in den ambulanten Diensten“ [“Outpatient care providers work with informal carers”]	“Nationale und internationale Forschungsergebnisse zur Situation von pflegenden Angehörigen – Unterschiedliche Perspektiven von Angehörigen und ambulanten Diensten” [“National and international research results concerning the situation of family carers – The different perspectives of family carers and providers”]
2005-09-15 **Hamburg** (2 hours)	Die Brücke Counselling Agency for older people and their relatives	Special Workshop	Family Carers	“European Charter for Family Carers”– What are the wishes of family carers concerning awareness and support?	“Europäische Charta für pflegende Angehörige” – Welche Aufmerksamkeit und Unterstützung wünschen sich pflegende Angehörige? [“European Charter for Family Carers” – What arte the wishes of family carers concerning awareness and support?]
2005-09-13 to 15 **Erfurt** (3.5 hours)	DRK Generalsekretariat [General Secretariat of the German Red Cross]	Bundeskongress Altenhilfe [Federal Congress on Care for the Elderly]	GeschäftsführerInnen. Leitungskräfte, FachreferentInnen [Chief executive Officers; Heads of Institutions; Representatives]	“Altenhilfe und Gesundheitsförderung“ [“Care for Elderly and Health Promotion”]	“Hilfen für Pflegende – Erwartungen und Inanspruchnahme von Entlastungsangeboten” [“Support for Family Carers – Expectations to and utilization of services”]

GERMANY

Date + location	Organiser	Kind of Event	Target group	Name of the Event	Title of Presentation
2005-10-11 **Berlin** (5.5 hours) (30 minutes presentation with discussion)	Sozialverband Deutschland e.V. & Ver.di [Social alliance Germany and Ver.di (labour union)]	National Congress of “Sozialverband Deutschland SoVD“ in cooperation with “Vereinte Dienstleistungsgewerkschaft ver.di” (German trade union) – Plenary session with 7 presentations and a round table	Service providers; elderly’ organisations; caregivers’ organisations, health authorities; social care authorities; researchers; politicians, unionists, members of gender equality groups, others	“Die Stärkung der häuslichen Pflege – Eine Herausforderung für Politik und Gesellschaft“ [“Support for care at home – A challenge for policy and society”]	"Unterstützung und Entlastung für pflegende Angehörige älterer Menschen im europäischen vergleich” [“Caring for Carers: A European comparative study on support for family carers of older people”]
2005-10-17 Hamburg (3 hours)	Katholische Akademie [Catholic Academy]	Bildungsurlaubsseminar [Educational Leave Seminar]	Interessierte Menschen ab 40 [Interested People around 40 and older]	“Wenn wir älter werden… Älter werden in Europa“ [“When we grow old… Ageing in Europe.”]	“Familienbeziehungen und Pflege im Alter – Ein europäisches Projekt und seine Bedeutung für die Sozial- und Gesundheitspolitik innerhalb Europas” [“Family relationships and care for the elderly – A European project and its meaning for the social and health policies in Europe”]

Not mentioned here: Publications / press releases / other mainly scientific presentations as well as presentations on European level (as described in the final report in the part “Exploitation and dissemination activities”)

Overview of the REACT activities performed in Germany in 2005

EUROFAMCARE	**Research Action (REACT) activity Germany I**
Country	Germany
Data of the event	2005-08-10
Location	Hanover
Duration	2.5 Hours for EUROFAMCARE
Kind of the event	2 Days Workshop organised by the Diakonisches Werk der EKD and the Diakonisches Werk der ev.-luth. Kirche Hannovers
Name of the event	“Family carers – professionally canvassed”
Number of participants	20
Target groups	Mainly senior consultants of the federal organisations; heads of divisions of ambulatory services
Program	Our presentation was on the first day, first presentation after the introduction. Two more presentations followed

Structure of the presentation

- Overview EUROFAMCARE
- Short description of the EUROFAMCARE-Sample from the base study
- International results from the EUROFAMCARE-Study
- Different care situations
- Needs and expectations of family carers towards services – international comparison
- Presentation of German results
- What are the needs of German family carers?
- What kinds of services are used by German family carers?
- What kinds of services are used by older people?
- In general
- Classified by care levels
- Classified by kind of benefit
- Needs and expectations of family carers towards services

The participants showed higher interest in national results because these were closer to their practice. As senior consultants they were more interested in new developments and critical views on the work of providers than the members of the institution which are involved in practical care work. They look for gaps in services that might be interesting for their institution as new or modified offers.

Results on the European level, especially the European clusters describing the care situations, were of less interest for the audience. It seems to make more sense to focus on certain highlights of European results compared to Germany (e.g. noticeable characteristics of countries, like the enhanced understanding of the term “family care” in the UK or the high amount of caring spouses / partners in Sweden), not using the care situation clusters. At last, the type of service providers should be taken into account more. That means, e.g. in case of senior consultants from ambulatory services or domestic care are especially interested in results which deal with household or living situation characteristics as well as rural-urban-differences. The presented results should focus on action orientated information which is easily to adopt for the heads of divisions for their daily work.

Topics of special interest:

- The problem of reaching the target group of family carers was discussed based on our recruitment problems.
- In general, aspects which are currently on the agenda in the care sector in Germany, are of high interest for the participants. This means, results regarding cognitive impairment or the positive values and negative impacts of care giving are important to show.

EUROFAMCARE	**Research Action (REACT) activity Germany II**
Country	Germany
Date of the event	2005-09-15
Location	Hamburg, University building
Duration	4:00 pm to 6:00 pm
Kind of event	Special workshop in cooperation with a counselling centre for older people and their relatives
Name of event	European Charta for Family Carers – What are the wishes of family carers concerning awareness and support?
Number of participants	20 family carers and three social workers
Target groups	Family carers
Program	▪ Welcoming attending carers ▪ Short overview of event's objective and schedule ▪ Introduction of the EUROFAMCARE project and the idea of a EUROPEAN CARERS CHARTER ▪ Round of introductions of the family carers ▪ Discussion with carers about controversial charter issues: ▪ Who should be primarily responsible for the care of elderly people? ▪ Scholars and providers of care discuss the issue whether carers are experts, clients, partners or workers ▪ Compatibility of care and occupation ▪ Should the receipt of services be tied to counselling?

Summary

Staff of the project EUROFAMCARE and the counselling centre for older people and their relatives of the HAMBURGISCHEN BRÜCKE invited caring relatives to a discussion of their desires and ideas to ease their care situation. The invitations were issued via the counselling centre, the Hamburg Alzheimer Association and an announcement in the local paper. For people in need of care suffering from dementia care was provided, however, this offer was not used.

After a short introduction of the project and the idea of a EUROPEAN CARERS CHARTER family carers were asked to introduce themselves and their cared-for using a catalogue of questions (Name, who do you care for, how long have you been performing this task, where do you care for your relative, does a grade of dependency exist, what is the reason for need of care, was dementia diagnosed) In addition, participants were asked to shortly state what they perceive to be the greatest burden or help in the care situation. In the second part of the event, the actual discussion took place in which selected questions were asked.

The (unexpected) high turnout clarifies carers' need to talk about their situation and inform a broader public about their situation (5 participants attended based on a small advertisement in a local paper). Most participants seemed to be under great psychological stress. The desire for the recognition of their work and support is very high. Especially relatives of people suffering from dementia mourn the lack of understanding the public (society, neighbours, friends, doctors) has for their situation and also for the behaviour of the cared for:

- Relatives feel left alone with their task
- Relatives desire more recognition for their work
- Relatives want to be treated with respect (from doctors as well) and receive support
- Relatives want the possibility to combine employment and care
- Relatives do not perceive the decision to assume care as their free choice
- Relatives feel a financial burden caused by the care

Overall, the event was very interesting and manifested the complex care situation of caring relatives. Of special importance for the charter were statements regarding the causes of strain and the compatibility of care and occupation.

EUROFAMCARE	**Research Action (REACT) activity Germany III**
Country	Germany
Data of the event	2005-09-13 to 15
Location	Erfurt, Secretariat of the German Red Cross
Duration	9:30 am to 1:00 pm
Kind of the event	Federal Congress on Care for the Elderly, Info shop
Name of the event	“Care for Elderly and Health Promotion”
Number of participants	15
Target groups	Service providers; Chief executive Officers; Heads of Institutions; Representatives
Program	Two days Congress. The Presentation took place on the first day and was organized as an “Info shop”. The presentation and discussion alternate more or less half-hourly.

Structure of Presentation

- Overview EUROFAMCARE
- Short description of the EUROFAMCARE-Sample from the base study
- Target group
- Sample characteristics
- International results from the EUROFAMCARE-Study
- Different care situations
- Needs and expectations of family carers towards services – international comparison
- Presentation of German results from the EUROFAMCARE-Study
- What are the needs of German family carers?
- What kinds of services are used by German family carers?
- What kinds of services are used by older people?
- Needs and expectations of family carers towards services

The participants were very interested in the different needs and expectations of family carers toward services in the countries and they discussed the configurations of welfare states in our study and the impact on different needs.

But in general they showed higher interest in national results because these were closer to their practice. The main discussion point was the discrepancy between a diversified offer of support like information, counselling and training in Germany on the one hand and the lowly use of this offer by family carers on the other hand. They discussed whether the assessment of family care situation and the training of family carers in the framework of the long-term care insurance should be more compulsory than it is nowadays. Every person in need of care asking for benefits from the long-term care insurance has to be assessed as a prerequisite for the decision on the care level (amount of help in cash or in kind. The assessor should take this possibility to give much more advice for family carers who decide for cash benefits to reduce the barriers for the use of services offered especially decrease the burden.

EUROFAMCARE	**Research Action (REACT) activity Germany IV**
Country	Germany
Data of the event	2005-10-11
Location	Berlin
Duration	11:00 am to 4:30 pm
Kind of the event	National Congress of „Sozialverband Deutschland SoVD“ in co-operation with “Vereinte Dienstleistungsgewerkschaft ver.di” (German trade union)
Name of the event	“ Support for care at home– A challenge for policy and society”
Number of participants	250
Target groups	Service providers; elderly’ organisations; caregivers’ organisations, health authorities; social care authorities; researchers; politicians, unionists, members of gender equality groups, others
Special guests	Members of Parliament
Program	▪ Plenary session with 7 presentations and a round table: The title of the presentation of the EUROFAMCARE Project was: “Caring for Carers: A European comparative study on support for family carers of older people” ▪ Project overview ▪ Target group ▪ Sample characteristics ▪ Different care situations in Europe ▪ Motivation for caring ▪ Financial motives and the German LTCI

Summary

The event took place in the house of the German trade union ver.di with the topic “ The fortification of family care – A challenge for policy and society”. 250 participants from all spheres of care, unionists, politicians and others. The presentation of the EUROFAMCARE project took 30 minutes. Afterwards the results where discussed. This took also round about 30 minutes.

The participants were especially interested in the following aspects:

- The problem of reaching the target group of family carers was discussed based on our recruitment problems.
- The audience was also very interested in the reasons for care giving and a longer discussion took place about the different motives for care in the six countries.

Because between the participants there were a lot of members of gender equality groups, especially the results about the financial motives for caring combined with the allowances from the German long-term care insurance were discussed. This leads to aspects like payment for family care in general and the question of the compatibility of family and work.

EUROFAMCARE	**Research Action (REACT) activity Germany V**
Country	Germany
Data of the event	2005-10-17
Location	Hamburg Katholische Akademie
Time	3:00 pm – 6:30 pm
Kind of event	Educational leave seminar with the topic "When we grow older – Family relations in Europe"
Name of event	Family relations in Europe
Number of participants	36
Target groups	Service providers; elderly's organisations; caregivers' organisations, health authorities; social care authorities; researchers; others
Program	Presentation of EUROFAMCARE project Project overview Motivating relatives to assume care and continue with care Expectations from services: Importance of forms of support and characteristics of services. Results from relatives' point of view Short presentation European Charter of family carers Discussion about the articles of an European Carers Charter

Summary

The event took place in the scope of an educational leave seminar with the topic "When we grow older – family relations in Europe". 36 participants came from seven federal states, the majority of them were between 60 and 70 years old. In the first 90 minutes, the EUROFAMCARE project was introduced, interrupted by many questions. Afterwards, the possible contents of a European Charter for Family Carers were presented and discussed.

The participants were especially interested in the following aspects:

- The effects of the long-term care insurance on the strain of relatives and the utilisation of services
- The relation of hours of home care provided to in-patient care
- The category "no memory but behavioural problems" was criticised as being too vague, as the cognitive restrictions do influence the behaviour

The slide "relatives of cared for with behavioural problems and without cognitive limitations" caused reactions. One participant commented that this presentation was the first time that she has heard something about the special strain of relatives caused by behavioural problems from professionals.

The question where they receive information from was answered differently by participants depending on the region they came from: One standard sized name for all German advisory boards for old people and their relatives would be very helpful.

Discussion regarding the European Charter for Family Carers:

The main responsibility for care is closely tied to the obligation to financial support on the children's side in Germany. Without the responsibility, active care and financial support of families, care in Germany cannot be afforded. Responsibility does not necessarily mean assuming the care.

Home care is seen as the better care, because nursing homes are seen so negatively. Home care is always a makeshift solution, alternative living arrangements are too rarely taken into consideration.

Compatibility of care and occupation is necessary as the number of singles who have to support themselves is rising. Thus, more flexible working hours are desired. In addition, the chances and risks by hiring migrants to assume care were discussed.

Passive information is not enough. Providers have to spread information using organisations, churches, local events and local radio stations and those who work with the target group.

Overall, interest in this topic and participation in the discussion was high. Some, however, were overwhelmed by the complexity of the presented results. It would be sensible to reduce the tables and only present the most central figures for this audience.

REACT: Action plan for Germany

Family carers in Germany complain about an enormous deficiency of information, in particular related to available support offers but also related to the illness of the elder person and the further course of the illness. They would like to have appropriate offers that enable them to take time off from care giving. Moreover, many relatives suffer from the lack of appreciation and recognition of their work by the society, but also by their families and the providers of services. Relatives think that an interchange with other persons is very important, but only few of them are involved in carers' groups. Many offers are felt to be too expensive, the bureaucratic procedure is a barrier, and the compatibility of care and employment often reaches limits that causes many women to give up their employment. And last not least, it is often difficult to reach the relatives, because they do not see themselves as "family carers".

On the other hand, the providers of services in the health, care and social sectors are very interested in reducing the deficiency of information, in closing gaps in the care giving system and providing appropriate support for family carers, but they often do not have access to the target group. The profusion of widespread information material (brochures, guides, flyers, journals, internet, information events, etc.) reaches the target group rarely or too late, and existing offers are often hardly utilised. There is a certain helplessness regarding the decision which alternative procedures should be developed.

An important result of the REACT phase in Germany is the awareness that the conventional way of imparting information apparently does not reach the target group or reaches it too late, i.e. it is not successful. The discussion events showed that family carers do not need another written guide. Therefore, the German project group decided not to produce a written guide for relatives, as had been the intention at the start of the project. Based on the project results, other priorities were chosen, because they promised greater success and a better response to the family carers' needs of appreciation and support.

We propose to found a national organisation for family carers in Germany. So far, there was no German-wide organisation of this kind. There exist mostly self-help initiatives for particular clinical picture, e.g. the Alzheimer association or the brain league, where carers are involved, and meanwhile there are a few regional carers' initiatives. But what is really required is a German-wide initiative that would bring together the existing regional associations and would stimulate new ones; they should all have the same name and telephone number – comparable to the police and emergency doctors – and they should be able to represent the interests of carers also on the political level.

The first steps are already taken. We designed a questionnaire that was sent to European countries such as Ireland, Scotland, UK, Sweden, Finland, The Netherlands, Belgium, France and Malta (in foundation), which had founded national organisation for family carers in the last years an devaluated these models of good practise.

In order to detect which type of organisation is appropriate for the German situation, we plan to carry out a workshop with representatives of various interests groups in order to discuss necessities, aims, tasks and possible sponsorship. A letter has already been sent to the Ministry for family, women, seniors and youth, asking for their support.

2.2 Italy

ITALY					
Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
2004-11-03 / 07 **Florence, Italy**	Italian Society of Gerontology and Geriatrics	National Congress	Geriatricians & other clinicians, researchers, policy makers	49th National Congress of the Italian Society of Gerontology and Geriatrics	EUROFAMCARE study: family care of older people in Italy: preliminary results. Four presentations on: ▪ introduction on aims of the study ▪ metholodogy ▪ family carers of older people suffering from dementia ▪ support networks and use of health and social care services
2005-04-21 **Graz, Austria**	Sociology Association of the Graz University	Guest Lecture	Local researchers and policy makers	The workshop "Neue Modelle der Altenbetreuung in Europa: theoretische Ansätze und empirische Befunde"	Supporting family carers of the elderly in Europe: some preliminary findings from the EUROFAMCARE project (guest lecture)
2005-04-22 **Graz, Austria**	Kompass (local care provider)	Keynote speech	Local and regional researchers, policy makers and students of social work	The International symposium "Strategies against social exclusion of older persons. Lessons learned from practice"	Risks of marginalisation in the European Care Systems: comparative comments on the CARMA findings (keynote speech)
2005-10-29 **Paris, France**	NOVARTIS (pharmaceutical industry)	International symposium	150 members of French Parliament	International Congress on "Proximology" (care-giving) in Europe	Family care of the elderly in Italy

ITALY

Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
September-November 2005 **Main sites of EUROFAMCARE data collection in Italy**	INRCA in collaboration with local service providers or carers' organisations	Presentations to local, regional and national policy makers and service providers	local, regional and national policy makers and service providers	Presentation of main EUROFAMCARE findings: relevance for policy and service provision	Main findings related to local situation of family carers of older people (In Italian)
2005-11-17 **Hamburg**	University of Hamburg	Final conference of EUROFAMCARE project	Representatives of national organisations of family carers and policy makers	Final conference of EUROFAMCARE project	1) Services for family carers: characteristics, usage and acceptability 2) Financial effects of caregiving: employment, income loss and value of family care
2005-12-6	AGE – Older people's platform	Presentation to MEPs	MEPs and European organisations in this field	Family care of older people in Europe	Family carers of older people and use of support services in Europe: main findings from the EUROFAMCARE survey
2005-12-22	Italian Ministry of Health	Workshop presentation	A delegation of public care service providers from Spain	Workshop "Family care of the elderly in Italy"	Support services for family carers of dependent older people in Italy: synthesis of main fundings from the European research project EUROFAMCARE (in English and Italian)
2006-03-15	Disability Commission of the Italian Government	Workshop	Policy makers and service providers	Care policies for dependent older people in Italy	The need for supporting services for family carers of older people in Italy
2006-05-12	Ferrero Foundation	Conference	Policy makers, service providers and researchers	Well-being in older age	The role of family carers of older people in Italy

Not mentioned here: Publications / press releases / other mainly scientific presentations as well as presentations on European level (as described in the final report in the part "Exploitation and dissemination activities")

Overview of the REACT activities performed in Italy in 2005

EUROFAMCARE	**Research Action (REACT) activity Italy as above**
Country	Italy
Data of the event	See above section 2
Location	See above
Duration	See above
Kind of the event	See above
Name of the event	See above
Number of participants	Between 10 and 100, depending upon the event.
Target groups	Service providers; elderly's organisations; caregivers' organisations, health authorities; social care authorities; researchers; others
Special guests	Some relevant representatives at national level of public authorities, family carers' organisations and service providers.
Programme	See above

What are the specific aims of this initiative / action?

The main aim of the undertaken initiatives was to provide up-dated empirical evidence of the situation of Italian family carers in an European comparative perspective. These data could be used by service providers, policy makers as well as service users' and carers' organizations to revise existing policies and strategies in the field of support services for family carers towards a more partnership based approach at a local, regional, national and European level.

Which methods are we using by means of this initiative / action to reach the above aims?

The main method used to provide the above has been workshops, conference, and oral presentation at different kinds of meetings. Another method, which is expected to become more relevant in the next future, is represented by articles, reports and other written publications (also downloadable from the internet), which require more time to be finalized than oral communications.

What are the expected results from this initiative / action?

The undertaken initiatives are expected to induce a rethinking of the "older person - family carer – service provider – policy maker" relationship, in order to achieve a more balanced partnership among the involved actors to find more appropriate solutions to the growing issue of the long term care of our ageing society.

(Afterwards) **Wat are the actually achieved results?**

So far the results have been limited to the enthusiastic feed-back from some of the participants of these initiatives, however in the next future also some practical impact could take place, in form of modification / integration of current measures at a local or national level.

Which suggestions can be derived out of this initiative for future actions / steps?

A more systematic approach is needed by the care system in order to provide a more tailored care, which is able to take into account both the needs of the older persons and those of their family carers. This however requires on turn the concurrent involvement of all relevant actors (users, family carers, providers and policy makers) at all crucial stage of the caring process (provision, organisation, implementation and planning), in order to ensure an acceptable level of care quality, as an essential indicator of the society's ability to grant respect and dignity also to its weakest members.

REACT: Action Plan for Italy

The dissemination of the findings emerging from the EUROFAMCARE study has started already in the late months of **2004** with a presentation of the preliminary results (from the data collection carried out on 1,000 family carers in the early months of the same year) at the National Congress of the Italian Society of Gerontology and Geriatrics (ISGG). In **2005**, presentations have been held in different events attended by Italian policy makers and care service providers. These were in particular the following: the National Congress of the ISGG; the final international conference of the project (where representatives of the Italian Ministry of Health and of two of the most relevant Italian NGOs in the field of family carers of the elderly have been invited); the presentation organised by AGE (The European Older People's Platform) to present the EUROFAMCARE findings to Members of the European Parliament (which was attended also by some Italian MEPs); a workshop organised by the Italian Ministry of Health to present the Italian care system (including the EUROFAMCARE findings on the condition of Italian family carers) to a delegation from the Spanish Ministry of Health; the inclusion of the family care-giving issue within a national report written on behalf of the Parliamentary Authority for Statistical Information by the Italian Premiership on the topic of "Statistical information on the care of the dependent elderly in Italy"; and the dissemination of preliminary findings in the main local sites where EUROFAMCARE data have been collected. In **2006**, the latter activity will continue with the translation and consequent dissemination of the project's Trans European Survey Report (TEUSURE) and Italian National Survey Report (NASURE) at all relevant levels (local, regional and national), two major events being already planned for next March (a workshop organised by the responsible for the Disability Commission of the Italian Government) and next May (a conference organised by the Ferrero Foundation on "well-being in older age"). Contacts are currently being held with the two NGOs in order to plan possible common activities to raise awareness on the issue of family carers among Italian policy makers and service providers.

2.3 Sweden

SWEDEN					
Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
2005-05-10 **Varberg**	The Family caregiver consultant in Varberg municipality	National conference Lecture and workshop	Family caregivers, Service providers, Politicians, Policymakers Researchers, Voluntary organisations	The Family caregiver Parliament	Service support for Family caregivers, EUROFAMCARE a study in six countries
2005-10-06 **Linköping**	The centre of Older people	Regional conference Lecture	Family caregivers Older people Service providers Politicians Policymakers etc.	Family caregivers day event	Service support for Family caregivers, EUROFAMCARE a study in six countries
2005-10-06 **Linköping**	Linköping municipality	Regional conference Lecture	Family caregivers Service providers Politicians Policymakers Voluntary organisations etc.	Family caregivers day event	Service support for Family caregivers, EUROFAMCARE a study in six countries
2005-10-03 **Linköping**	IHS, Linköping university	Seminar	Researchers	Research seminar	Service support for Family caregivers, EUROFAMCARE a study in six countries
2005-10-24 **Linköping**	IHS, Linköping university	Seminar	Senior researchers Doctoral students	IHS-seminar	Measuring family carers quality of life – how to be used in health economics
2005-11-25 **Stockholm**	Ersta Sköndal university college	Seminar	Service providers Students	Education seminar for social workers	The service usage for carers in Sweden
2005-11-30 **Stockholm**	The Swedish Society of Medicine	National conference	Physicians, Psychiatrists Researchers	The Annual General Meeting of the Swedish Society of Medicine	Service support for Family caregivers, EUROFAMCARE a study in six countries

SWEDEN					
Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
2006-02-02 **Kisa**	The centre for Older People, Östergötland	Local conference Lecture and discussion	Family carers, Older people, Service providers Politicians Policymakers etc	The centre for Older People – Café for development and research	Service support for Family caregivers, EUROFAMCARE
Not mentioned here: Publications / press releases / other mainly scientific presentations as well as presentations on European level (as described in the final report in the part “Exploitation and dissemination activities”)					

Overview of the REACT activities performed in Sweden in 2005

EUROFAMCARE	**Research Action (REACT) activity Sweden (as above)**
Country	Sweden
Data of the event	See above
Location	See above
Duration	See above
Kind of the event	See above
Name of the event	See above
Number of participants	Between 15 and 500, depending upon the event.
Target groups	Service providers; elderly' organisations; caregivers' organisations, older people; caregivers; health authorities; social care authorities; researchers; media; others
Special guests	Relevant representatives at national, regional and local level of public authorities, family carers' organisations and service providers have been invited and participating.
Programme	See above

What are the specific aims of these actions?

The main aim of the performed activities was to make empirical evidence available of the situation of family carers' situation and service use in Sweden but also in a six-country European comparative perspective. This knowledge could be used by service providers, policy makers as well as service users' and carers' organisations in development of policies and strategies that concern services support for family carers. The activities are also aimed to increase the partnership based approach between family carers, older people and service providers at a local, regional, national level.

Which methods are we using by means of these actions to reach the above aims?

The main method used to provide the aim has been oral presentation, discussions and workshops at different meeting arrangements. A method planned for future activities is written publication represented by articles, reports and other (as electronic information available by the internet). However these require more time to accomplish.

What are the expected results from these actions?

The performed activities are expected to supply useful knowledge that could be used by service providers, policy makers as well as service users' and carers' organisations in development of policies and strategies that concern services support for family carers. The activities could also increase the awareness of a needed partnership based approach in the interaction of family carers, older people and service providers at a local, regional, national level.

What are the actually achieved results?

The results consist of feed-back from the participants so far. The feed-back confirms our empirical results but also show that our study offers new information that is asked for by policy makers and service providers. The interest from the participants might in the next future also lead to some practical impact, in form of modification / integration of current measures at a local or national level.

Which suggestions can be derived out of these initiatives for future actions / steps?

A systematic approach is needed by the care and support systems that take in to account the needs of older people as well as of family carers. This requires involvement of all relevant actors (users, family carers, providers and policy makers) at all crucial stage of the caring process (provision, organisation, implementation and planning). The challenges for the service providers are to really recognise involved family carers and to develop fitting support at an individual level. There is also a need for systematic service evaluation in order to ensure and improve the service quality, as an essential indicator of the society's ability to grant respect and dignity to older people and family carers.

REACT: Action plan for Sweden

The future action plan is to write a Swedish report to be publicized in collaboration with The National Board of Health and Welfare presenting the most important results from the EUROFAMCARE project about the situation of family carers' situation and service use. The report will be available for decision makers, service providers, family carers and others. In Sweden it is the authorities at different levels that are responsible for developing guidelines. This information will be possible to use together with other facts and considerations in the development of guidelines.

A short summary of the empirical findings of the Swedish EUROFAMCARE project has been made available as the Swedish deliverable of REACT.

2.4 Poland

POLAND					
Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
2005-01-21 **Sokolka**	Sokolka Municipality and Podlaski Branch of the Polish Society of Gerontology	1 / Conference with 2 / workshop	researchers, service providers, NGO representatives, local authorities as well as policy makers	1 / "Sytuacja opiekunów rodzinnych ludzi starych niesprawnych w Polsce" ["Situation of family carers of older people in Poland"] 2 / "Mozliwosci wdrozenia rozwiazan lokalnych i systemowych dla poprawy sytuacji rodzin sprawujacych opieke nad osoba starsza niesprawna- opiekun rodzinny jako partner w systemie" ["Possibilities of initiate local and system solutions for improving situations of families caring for older people – family carer as the partner in the system"]	1. Założenia metodologiczne badan EUROFAMCARE (B. Bień) 2. Pozycja opiekuna rodzinnego osoby starszej niesprawnej w Polsce- aspekty prawne (NABARE) (W. Pedich) 3. Społeczno-medyczna charakterystyka niesprawnych podopiecznych rodzin (B. Bień) 4. Społeczno-demograficzna charakterystyka opiekunów osób starszych niesprawnych- potencjalne zagrożenia w związku ze sprawowaniem opieki (P. Czekanowski) 5. Usługi wspierające rodzinę z niesprawnym starszym podopiecznym- perspektywa odbiorców usług (B. Wojszel) 6. Usługi wspierające rodzinę z niesprawnym starszym podopiecznym- perspektywa świadczeniodawców usług (P. Błędowski) 7. Zasoby wojewodztwa podlaskiego w aspekcie wspierania rodzin sprawujących opiekę nad osobą starszą niesprawną (L. Micun)

POLAND					
Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
2005-06-18 **Bialystok**	Department of Geriatrics, Medical University of Bialystok & Polish Society of Gerontology	1 / Symposium with 2 / workshop	Researchers, service providers, NGO representatives, local authorities as well as policy makers	1 / Eurofamcare Symposium during the Xth Congress of Polish Society of Gerontology 2 / Jak wspierać opiekuna rodzinnego osoby starszej niesprawnej? Rola Państwa, Świadczeniodawców Formalnych i Nieformalnych [How to support family carer of disabled older person? The role of state, formal and informal providers] during the Xth Congress of Polish Society of Gerontology	1. Założenia i cele projektu badan EUROFAMCARE (B. Bien) 2.Metodologiczne założenia badań EUROFAMCARE (B.Synak) 3. Pozycja opiekuna rodzinnego osoby starszej niesprawnej w Polsce (W. Pedich) 4. Starsi wiekiem podopieczni polskich rodzin w świetle badań EUROFAMCARE (B. Bień) 5. Charakterystyka polskiego opiekuna rodzinnego osób starych w badaniach EUROFAMCARE (P. Czekanowski) 5. Usługi wspierające rodzinę sprawującą opiekę nad osobą starszą- w świetle wyników badań EUROFAMCARE w Polsce (B. Wojszel) 6. Usługi wspierające rodzinę z niesprawnym starszym podopiecznym ocenie świadczeniodawców (P. Błędowski)
Not mentioned here: Publications / press releases / other mainly scientific presentations as well as presentations on European level (as described in the final report in the part “Exploitation and dissemination activities”)					

Overview of the REACT activities performed in Poland in 2005

EUROFAMCARE	**Research Action (REACT) activity Poland I**
Country	Poland
Data of the event	2005-01-21
Location	Sokolka / Bialystok
Duration	4 hours
Kind of the event	1 day conference connected with workshop organised by the Sokolka Municipality and Podlaski Branch of the Polish Society of Gerontology
Name of the event	Conference: "Sytuacja opiekunów rodzinnych ludzi starych niesprawnych w Polsce" [“Situation of family carers of older people in Poland”] Workshop: "Mozliwosci wdrozenia rozwiazan lokalnych i systemowych dla poprawy sytuacji rodzin sprawujacych opieke nad osoba starsza niesprawna – opiekun rodzinny jako partner w systemie” [“Possibilities of initiate local and system solutions for improving situations of families caring for older people – family carer as the partner in the system”]
Number of participants	100
Special guests	representatives from Lithuanian partner (Calvarias), Margerita Jaroszuk (representative of the Department of Social Policy of the Province Government in Bialystok), Wojciech Tomal (Director of the Department of Health and Social Policy of the Marshal’s Government in Bialystok), Elzbieta Chojnowska (National Fund of Health, Podlaski Branch), Miroslaw Szyfman (Director of the Polish Red Cross), Joanna Starega-Piasek (Director of the Institute for Social Services Development, Warsaw), Jerzy Gierlacki (Specialist in the Department of Social Help, the Polish Government)
Target groups	researchers, service providers, NGO representatives, local authorities as well as policy makers on regional and national level
Program	Project presentations of the Polish team members were followed by the workshop with panel discussion

It was a conference and workshop organized by Sokolka Municipality and Podlaski Branch of the Polish Society of Gerontology, as a part of EUROFAMCARE Project as well as a Project “Aktywizacja transgranicznej wspolpracy w zakresie zdrowia publicznego” [“Stimulation of trans-border cooperation in public health”], with the participation of representatives from Lithuanian partner (Calvarias). The place of the event was localised in one of the regions involved in the EUROFAMCARE Project (Podlaski Region).

Structure of the presentation

- Zalozenia metodologiczne badan EUROFAMCARE [Methodological aspects of EUROFAMCARE Study] (B. Bień)
- Pozycja opiekuna rodzinnego osoby starszej niesprawnej w Polsce- aspekty prawne (NABARE) [Position of family carer of disabled older person in Poland – law aspects] (W. Pedich)
- Spoleczno-medyczna charakterystyka niesprawnych podopiecznych rodzin [Socio-medical characteristics of disabled cared for by family] (B. Bień)
- Spoleczno-demograficzna charakterystyka opiekunow osob starszych niesprawnych – potencjalne zagrozenia w zwiazku ze sprawowaniem opieki [Socio-demographic characteristics of family carers of disabled older people – main threats connected with caring] (P.Czekanowski)
- Usługi wspierajace rodzine z niesprawnym starszym podopiecznym – perspektywa odbiorcow usług [Services supporting family caring for disabled older person – services clients’ perspective] (B. Wojszel)
- Usługi wspierające rodzinę z niesprawnym starszym podopiecznym – perspektywa swiadczeniodawcow usług [Services supporting family caring for disabled older person – service providers’ perspective] (P. Błędowski)
- Zasoby wojewodztwa podlaskiego w aspekcie wspierania rodzin sprawujących opiekę nad osobą

EUROFAMCARE Research Action (REACT) activity Poland I

- starszą niesprawną [Podlaski region resources in supporting families caring for disabled older persons] (L. Micun).

During the conference on “Situation of family carers of older people in Poland” the Polish team has presented national results of the EUROFAMCARE Project. The participants showed high interest in the results presented as well as in the results on the European level. Participants were: representatives of local authorities, policy makers on regional and national level as well as health care and social care workers and members of NG organization from the Podlaski Region.

Project presentation was followed by the workshop on “Possibilities of initiate local and system solutions for improving situations of families caring for older people – family carer as the partner in the system”. It was underlined that services for family caring for older member are first of all medical ones, targeting medical needs of older persons. There is lack of the social services and coordination of activities directed at families caring for older people.

The main conclusions presented by professor W. Pedich were:

- Organizers of care should recognise family carers and treat them as partners as well as create the wider range of supportive services for family carers.
- Policy makers should create social policy towards family carers on local and national level (for instance law regulations concerning support directed at family caring for older people; development of infrastructure, support of information)
- Family carers should organize themselves in self-support groups, to exchange the experiences and to influence on media (TV / radio) to increase presenting problems of older people and the important role of family carers.

EUROFAMCARE	**Research Action (REACT) activity Poland II**
Country	Poland
Data of the event	2005-06-18
Location	Bialystok
Duration	4 hours
Kind of the event	Symposium and workshop during the Xth Congress of Polish Society of Gerontology
Name of the event	1 / Eurofamcare Symposium 2 / Workshop: “Jak wspierać opiekuna rodzinnego osoby starszej niesprawnej? Rola Państwa, Świadczeniodawców Formalnych i Nieformalnych” [“How to support family carer of disabled older person? The role of state, formal and informal providers”] during the Xth Congress of Polish Society of Gerontology
Number of participants	60
Target groups	Researchers, service providers, NGO representatives, local authorities as well as policy makers
Programme	Project presentations of the Polish team members were followed by the workshop with panel discussion

It was a symposium and workshop organised by the Department of Geriatrics, Medical University of Bialystok & Polish Society of Gerontology, as a part of 10th Congress of Polish Society of Gerontology. The place of the event was localised in one of the regions involved in the EUROFAMCARE Project (Podlaski Region).

Structure of the presentation

- Załozenia i cele projektu badawczego EUROFAMCARE [Assumptions and aims of EUROFAMCARE Study] (B. Bien)
- Metodologiczne założenia badan EUROFAMCARE [Methodology of EUROFAMCARE Study] (B. Synak)
- Pozycja opiekuna rodzinnego osoby starszej niesprawnej w Polsce [Position of family carer of disabled older person in Poland] (W. Pedich)
- Starsi wiekiem podopieczni polskich rodzin w swietle badan EUROFAMCARE [Older persons cared for by families in light of EUROFAMCARE Project results] (B. Bien)
- Charakterystyka polskiego opiekuna rodzinnego osob starych w badaniach EUROFAMCARE [Characteristics of the Polish family carer of older person in EUROFAMCARE Project] (P.Czekanowski)
- Usługi wspierajace rodzine sprawujaca opieke nad osoba starsza – w swietle wynikow badan EUROFAMCARE w Polsce. [Services supporting family caring for older person – in light of EUROFAMCARE results] (B. Wojszel)
- Usługi wspierajace rodzine z niesprawnym starszym podopiecznym w ocenie świadczeniodawcow [Services supporting family caring for disabled older person – service providers’ opinions] (P. Błedowski)

During the EUROFAMCARE symposium the Polish team has presented national results of the EUROFAMCARE Project. The participants showed high interest in the results presented as well as asked for preliminary results on the European level. Participants were first of all researchers involved in the field of geriatrics and gerontology, of different professions (doctors, nurses, social workers etc.) as well as representatives of local authorities, policy makers on regional and national level and members of NG organization from different regions in Poland.

Project presentation was followed by the workshop on “How to support family carers of disabled older person? The role of state, formal and informal providers”. It was underlined that family carers need first of all proper information. The same situation is in the case of service supporters. There is a problem of lack of good coordination in using resources available. Family carers are not recognised and supported. The only positive example is Alzheimer Society. The Polish Society of Gerontology (as the scientific and social society) should also support presentation of family carer’s problems for the wider society.

REACT: Action plan for Poland

During the year 2006 the results from the project will be disseminated further and first of all a national survey report will be published as a book "Family Care-giving for the Elderly in Poland: Results of the EUROFAMCARE project" (editor: B. Bien).

The Polish team members plan also to continue to participate in relevant conferences; at national level and at local level. We plan also to co-operate more with the Polish Society of Gerontology. The society is planning to conduct a scientific project connected with the development of the web page for caregivers of older people in Poland construction. This idea was based on the EUROFAMCARE project results in Poland. The Polish team members plan to cooperate in that project.

2.5 Greece

GREECE					
Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
2004-09-21 to 22 **Torun**	Polish Geriatric Society	Conference	Academics and policy makers	7th International Long–Term Care Conference “Family and Disability. Forms of Community Support”	PEUBARE – “Support Services for Family Carers of Dependent Older People in 6 EU Member States” Dr. J. Triantafillou
2004-09-27 to 28 **Brussels**	Austrian Institute for Family Studies and European Observatory	Seminar	Researchers, policy makers, academics	Annual Seminar of the European Observatory on the social situation, demography and the family	Feedback to Session 5: Family and health in an enlarged EU – issues of family carers from the EFC study
2004-10-21 to 23 **Venice**	PROCARE	Conference	Academics, researchers / policy makers	Providing Integrated care for older persons	The future of LTC for older persons – innovations in the EU Dr. J. Triantafillou
2005-03-31 to 2005-04-03 **Thessaloniki**	GARDA (Alzheimer’s Association, Northern Greece	Conference	Family carers, service providers, researchers, academics	4ου Πανελλήνιου Συνεδρίου Νόσου Alzheimer και Συναφών Διαταραχών [4th Panhellenic Conference on Alzheimer and other related diseases]	1. «Έρευνα EUROFAMCARE – Υποστηρικτικές υπηρεσίες για οικογενειακούς φροντιστές των εξαρτημένων ηλικιωμένων σε 23 χώρες στην Ευρώπη.» (PEUBARE) Dr.J.Triantafillou 2. “EUROFAMCARE – μια Ευρωπαϊκή έρευνα σε 6,000 οικογενειακοί φροντιστές εξαρτημένων ηλικιωμένων ατόμων και τα χαρακτηριστικά του Ελληνικού δείγματος (NASUR) Dr.C. Prouskas

GREECE

Date + location	Organiser	Kind of Event	Target group	Name of the Event	Title of Presentation
2005-09-16 **Athens**	Seminar of the European Network for Research on Supplementary Pensions	Seminar	Researchers, academics, policy makers	Law, Policy and Cultural Background in the Occupational Pensions Context	"The Role of Pensions in supporting Family Carers of dependent older people" Dr. E. Mestheneos
2005-12-16 **Thessaloniki**	GARDA (Alzheimer Association)	Meeting	Family carers	Regular meeting	Findings from PEUBARE and NASUR and the support of family carers. Dr. J. Triantafillou Dr.C. Prouskas
2006-01-30 **Athens**	Sextant in Department of Health Services Management	Meeting	Those at the NSPH, interviewers, interested parties	Special Presentation of EUROFAMCARE	Presentation of Results of study Dr. J. Triantafillou Dr.C. Prouskas, Dr. E. Mestheneos

Not mentioned here: Publications / press releases / other mainly scientific presentations as well as presentations on European level (as described in the final report in the part "Exploitation and dissemination activities")

Other activities and contacts affected and planned:

- EETAA (Hellenic Organization for the Development of Local Authorities) – agreement to publish selected findings in their journal that is distributed to all Local Authorities.
- National Association of Social Workers – agreement to publish articles in their national journal of social work.
- Meeting (7th February 2006) with NGO Social Participation.
- HAGG (Greek Geriatric and Gerontological) Society – intervention in one of seminars at the bi-annual conference.
- A section of HAGG concerned with the Psychological support of Family carers and a day care centre, residential unit etc. (NESTOR etc) will be inviting us to give a presentation of the results of EFC over the next months.
- A further activity that will affect the dissemination of the EFC results is the start up of the NGO "50+ Hellas" designed to provide information and advocate on behalf of older people. The first newsletter was produced at the end of January and the second newsletter, which is to be produced at the end of June, will contain a section on family care based on the results of the EFC. In part the results of the NASUR – where family carers insisted that they needed more information both about services and about the condition of the older person they cared for, convinced us of the necessity for such an NGO.
- We also made a contribution to the Ministry of Health and Social Solidarity's Structural plan for 2007-13 both as a written submission and as a comment at a conference held in December 2005 which we attended.
- We as Greek members of the EFC consortium and on their behalf will be making a presentation in the context of the International Federation on Ageing 31st May-3rd April in a workshop devoted to family care and organized with the EUROCARERS association.

Overview of the REACT activities performed in Greece in 2005

EUROFAMCARE	**Research Action (REACT) activity Greece I**
Country	Greece / in Poland
Data of the event	2004-09-21 to 22
Location	Torun, Poland
Duration	1 hour presentation - paper
Kind of the event	Academic
Name of the event	7th International Long–Term Care Conference “Family and Disability. Forms of Community Support”
Number of participants	100
Target groups	Those interested in LTC
Programme	Presentation of preliminary work from PEUBARE - “Support Services for Family Carers of Dependent Older People in 6 EU Member States.”

What are the specific aims of this initiative / action?

Contribution to debate on LTC

Which methods are we using by means of this initiative / action to reach the above aims?

Lecture- presentation

What are the expected results from this initiative / action?

Information at a European level to those involved in policy and research on LTC

EUROFAMCARE	**Research Action (REACT) activity Greece II**
Country	(Greece) EU
Data of the event	2004-09-27 to 28
Location	Brussels
Duration	2 days
Kind of the event	Annual Seminar of the European Observatory on the social situation, demography and the family.
Name of the event	Europe’s coming generations: demographic trends and social change - session 5. Family and health in an enlarged Europe
Number of participants	150
Target groups	Researchers, academics, policy makers

What are the specific aims of this initiative / action?

To introduce the EFC study and the issue of family carers to the Seminar participants within the general discussion on family and health and access to health care.

Which methods are we using by means of this initiative / action to reach the above aims?

Feedback on presentations and discussion

What are the expected results from this initiative / action?

More awareness at EU level of the need to support families caring for dependent older people

EUROFAMCARE	**Research Action (REACT) activity Greece III**
Country	Greece- Italy
Data of the event	2004-10-21 to 23
Location	Venice
Duration	1 hour for EFC
Kind of the event	Presentation in the context of the PROCARE final conference
Name of the event	“Providing integrated health and social care for older persons – Facing the challenges in Europe”, European Centre for Social Welfare Policy and Research and PROCARE
Number of participants	100
Target groups	researchers; others
Programme	EFC presentation – “The future of European research on innovation in long-term care for older persons – experience from the EUROFAMCARE project”

What are the specific aims of this initiative / action?

Interprogramme cooperation

Which methods are we using by means of this initiative / action to reach the above aims?

What are the expected results from this initiative / action?

Collaboration and meetings at national and international level between members of research programmes with some common aims e.g. family care of dependent older people and integrated care

(Afterwards) What **are the actually achieved results?**

Continued collaboration at national level

EUROFAMCARE	**Research Action (REACT) activity Greece IV**
Country	Greece
Data of the event	2005-03-31 to 2005-04-03
Location	Thessaloniki
Duration	1 hour
Kind of the event	Presentations in the context of an Academic Conference
Name of the event	4ου Πανελλήνιου Συνεδρίου Νόσου Alzheimer και Συναφών Διαταραχών [4th Panhellenic Conference on Alzheimer and other related diseases]
Number of participants	300
Target groups	Service providers; caregivers’ organisations, health authorities; social care authorities; researchers; others
Programme	2 presentations – 1. «Έρευνα EUROFAMCARE – Υποστηρικτικές υπηρεσίες για οικογενειακούς φροντιστές των εξαρτημένων ηλικιωμένων σε 23 χώρες στην Ευρώπη.» (PEUBARE) 2. “EUROFAMCARE – μια Ευρωπαϊκή έρευνα σε 6,000 οικογενειακοί φροντιστές εξαρτημένων ηλικιωμένων ατόμων και τα χαρακτηριστικά του Ελληνικού δείγματος (NASUR)

What are the specific aims of this initiative / action?

EFC researchers informed very relevant people as to the EFC research

Which methods are we using by means of this initiative / action to reach the above aims?

Information – re-invitation a year later

What are the expected results from this initiative / action?

Abstracts published in a special issue of the Greek periodical “Encephalos” (in Greek) March 2005.

EUROFAMCARE	**Research Action (REACT) activity Greece V**
Country	Greece / EU
Data of the event	2005-09-16
Location	Athens
Duration	EFC presentation – 1 hour
Kind of the event	Seminar of the European Network for Research on Supplementary Pensions
Name of the event	“Law Policy and Cultural Background in the Occupational Pensions Context”
Number of participants	25
Target groups	Researchers; policy makers
Programme	EFC presentation on “The Role of Pensions in supporting Family Carers of dependent older people”

What are the specific aims of this initiative / action?

To consider occupational pensions.

Which methods are we using by means of this initiative / action to reach the above aims?

They are a research / policy network.

What are the expected results from this initiative / action?

It is important for them to realise that family care represents a further insurance risk and to consider this in proposals.

(Afterwards) **What are the actually achieved results?**

Interest and information – probably the first time people had thought of this – so it got onto their intellectual agenda.

Which suggestions can be derived out of this initiative for future actions / steps?

Policy making occurs at all levels – it is important to influence whoever we can.

EUROFAMCARE	**Research Action (REACT) activity Greece VI**
Country	Greece
Data of the event	2005-12-16
Location	Thessaloniki
Duration	2 hours (4:00 pm to 6:00 pm)
Kind of the event	Meeting of GARDA (Alzheimer Association)
Name of the event	EUROFAMCARE – Presentation of Results of study
Number of participants	35
Target groups	Service providers; caregivers’ organisations
Special guests	Those who had participated in the interviewing
Programme	Presentation of EFC results – PEUBARE and NASUR

What are the specific aims of this initiative / action?

To inform family carers in N. Greece of the results of the study.

Which methods are we using by means of this initiative / action to reach the above aims?

Open lectures.

What are the expected results from this initiative / action?

Continuation of cooperation with GARDA.

EUROFAMCARE	**Research Action (REACT) activity Greece VII**
Country	Greece
Data of the event	2006-01-30
Location	National School of Public Health
Duration	2 hours
Kind of the event	Open invitation to attend presentation of results
Name of the event	EUROFAMCARE – Presentation of Results of study
Number of participants	23
Target groups	Researchers; others
Special guests	Those who had participated in the research were also invited.
Programme	Focus was on PEUBARE and NASUR

What are the specific aims of this initiative / action?

We have undertaken the research through the School and felt it appropriate that everyone in the NSPH was invited to attend and listen to the results. In fact just one person from the School attended; all the remainder were from outside.

Which methods are we using by means of this initiative / action to reach the above aims?

Signed invitation (signed by Dean and Professor) and distributed to relevant Departments in the School, to all those who had participated in the research and all others we knew might have some interest in the event.

What are the expected results from this initiative / action?

We had some interest from participants in dissemination.

(Afterwards) **What are the actually achieved results?**

We have undertaken our obligation to the School. There was great interest in the results and we shall be having further meetings with 2 organizations as a result of this meeting.

Which suggestions can be derived out of this initiative for future actions / steps?

Academics are not interested in this field.

EUROFAMCARE	**Research Action (REACT) activity Greece VIII**
Country	Greece
Data of the event	June 2005, October 2005, November 2005, Feb. 2006 – and other dates in the future
Location	Athens
Duration	1-2 hours each time.
Kind of the event	Meeting with President and leading associates of IKPA (Institute of Social Welfare and Solidarity
Name of the event	Agreement for cooperation
Number of participants	3-4
Target groups	Service providers

What are the specific aims of this initiative / action?

- To get PEUBARE translated into Greek – achieved.
- To ensure that NASUR will be translated into Greek – under negotiation.
- To present our findings in cooperation with IKPA in a day seminar event they will organise for their staff (service providers in social field throughout Greece).

Which methods are we using by means of this initiative / action to reach the above aims?

Discussions.

What are the expected results from this initiative / action?

To get family care on the Agenda in Greece.

Which suggestions can be derived out of this initiative for future actions / steps?

The need to identify and “convert” a key member of public organisations and bodies to the issues of family carers, in order to achieve any form of collaboration leading to actions.

2.6 The United Kingdom

UNITED KINGDOM					
Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
Northern Ireland – May 2005	UK EFC team	workshop	Senior practitioners and carers	n / a	UK findings from EFC presented followed by discussion and consideration of the findings, their use and most appropriate ways of dissemination.
Northern England – October 2005	UK EFC team	workshop	Middle line managers and representatives from voluntary organisations	n / a	As above
Wales – December 2005	UK EFC team	workshop	Policy makers and representatives of carer organisations	n / a	As above
Scotland – February 2006	UK EFC team	workshop	Family carers	n / a	As above

Overview of the REACT activities performed in the United Kingdom in 2005 / 06

EUROFAMCARE	**Research Action (REACT) activity UK**
Country	England, Northern Ireland, Scotland, Wales
Data of the event	2005-03-09 (N / I), 2005-10-17(England), 2005-12-01(Wales), 2006-02-02 (Scotland)
Location	Belfast (NI), Sheffield (England), Cardiff (Wales), Glasgow (Scotland)
Duration	Approximately 2.5 hours per session
Kind of the event	Meeting with President and leading associates of IKPA (Institute of Social Welfare and Solidarity)
Name of the event	EUROFAMCARE REACT: Reflections from the UK
Number of participants	Approximately 60
Target groups	Service providers; elderly organisations; caregivers' organisations, carers, policy makers, practitioners
Programme	See below (under methods)

What are the specific aims of this initiative / action?

- To present the results of the UK NASURE to key groups of policy makers, service providers, practitioners, carers' organisations, and carers, with a particular emphasis on issues to do with service quality.
- To ask participants to reflect on the above results and their implications for service design, delivery and evaluation.
- To discuss with participants their preferred method of disseminating the results.

Which methods are we using by means of this initiative / action to reach the above aims?

In order to ensure consistency the REACT events in the UK followed a similar format. The audience consisted of members of the stakeholder groups identified above, with specific events reflecting different groups. The event in Northern Ireland was attended mainly by senior practitioners and carers, the event in Sheffield by middle line managers and representatives of voluntary organisations, the event in Wales by policy makers and representatives of carer organisations, and the event in Scotland by carers themselves.

The events followed a similar pattern, beginning with an overview of the NASURE results in the context of the overall EUROFAMCARE project, followed by a consideration of a number of key issues. These were the implications for:

- a) the future provision of services / support for family carers;
- b) the monitoring / evaluation of services / support for family carers;
- c) the relationships between family carers and support services;
- d) professional training and education;
- e) the production of best practice guidelines and other training materials.

What are the expected results from this initiative / action?

To reach consensus on the main implications of the NASURE, and related results from a UK perspective, and / or to identify differences in viewpoints.

To consider the preferred method of disseminating the results.

(Afterwards) **What are the actually achieved results?**

All of the events were positively received, and the NASURE results generated considerable interest and prompted lively debate. Certain key issues were identified at each of the events, with particular prominence being given to:

- **1.** The importance of a partnership approach that recognised the contribution that carers make. The need for closer working between and within service agencies was a major concern. Potential tensions were identified between health and social care, with the former being seen to pay too little attention to carers' needs, and between the statutory and the voluntary sector, with the role of the latter being generally undervalued.
- **2.** The nature of carer assessment and service responses, with particular reference to:

Overarching principle of working with carers

- Carers should be treated as real and equal partners.

Carer Assessments: challenges to be met

- To identify why some carers are refusing assessments.
- Many carers, and some professionals, are not aware of a carer's right to an assessment – there is a need to raise awareness.
- There needs to be greater clarity about who conducts assessments.
- Current assessment can be inflexible and prescriptive. It should focus on identifying individual need rather than being target driven.
- Assessments are often a one-way process with information largely flowing from the carer to the assessor. Genuine two-way exchange of information is often inhibited by 'confidentiality' issues.
- There is a reluctance to record unmet need. This should be identified and used as a stimulus to develop more appropriate services.
- How can a balance be achieved between the needs of the carer and those of the cared-for person?
- A right to an assessment does not necessarily equate with a right to services.
- Many carers see assessment as a paper exercise, with little or nothing flowing from it.
- There is a need for a better mechanism of systematic review of carers' needs and ongoing assessment of these needs.
- There is a need for better staff training about assessment and a change in culture / attitudes towards carers.
- Attention was also given to a number of principles that should underpin good assessment practice, how an assessment should be conducted and the goals / outcomes that should be expected.

Principles of assessment

- Carers should participate as full partners in the assessment and also in the deciding the nature of subsequent services / support.
- Assessment should be carer-centred, person-focussed and start from 'where the carer is at'.
- Assessment should focus on individual need and not be service, target or performance indicator driven.
- Assessment must be meaningful to the carer and capture / reflect changes in their circumstances over time.
- It should be recognised that the process of assessment itself, if properly conducted, can be therapeutic.

Conducting the assessment

- It is essential to create an atmosphere in which the carer feels comfortable to express their views fully.
- The attitudes and skills of the assessor are essential to this.
- Assessment requires sufficient time, privacy and respect, and should be conducted with a non-judgemental attitude.
- Assessors must both listen to and hear what the carer is saying.
- Use of clear and jargon-free language is important.

Goals / outcomes of assessment

- Assessment should provide a broader understanding of the caring situation, carers' hopes and aspirations outside of caring, and those aspects of their lives that are important to them.
- Assessment should inform and empower carers to take greater control of their lives and enable them to access the resources they need to improve their quality of life.
- As a result of the assessment carers and assessors should together agree specific goals for support.

- The help / support provided should give carers real choice, and should they wish, focus on sustaining them in their caregiving role.

Service responses

General principles

- Services should improve the carers' quality of life and enable them to care more effectively.
- Services must be flexible, responsive, adequate, timely and of good quality. They need to be provided 24 / 7.
- Services should be proactive and provided early, rather than being largely reactive and crisis driven as they frequently are.
- There needs to be a better link between assessment and subsequent services, which should be "bottom up" and not "top down" and service driven.
- Services must be adequately resources but it should also be recognised that there is a need for greater creativity and innovation, with carers being actively involved in service design.
- There is a need for closer working and better sharing of information, particularly examples of good practice, between agencies.
- Improved systems of auditing and evaluating services need to be developed, with greater input from carers.

Specific services

- Direct payments – these were seen as potentially very useful but currently under resourced, and the system is not user friendly.
- Need for better, more flexible and innovative forms of respite.
- Help is needed to deal with conflict in relationships.
- Carers need help to develop more effective ways of coping.

- **3.** The characteristics of a good or quality service, and reasons why services are used or not, were discussed. The need for flexible, responsive, consistent and personalised services was a recurring theme. The skills and attitudes of care workers were seen as central, with there being a need to raise the profile and status of this work.
- **4.** The need for better and more reliable forms of information were another key concern. Carers often felt that professionals lacked the knowledge and understanding necessary to help them make informed decisions. Carers themselves often turned to the Internet and other sources in order to improve their access to information.
- **5.** Professionals need more training about carers' needs, and this should be introduced as early as possible into their education.
- **6.** Carers' rights should be established, especially those of exercising an informed choice and of being able to remain in employment should they so wish. Good domiciliary care was seen as essential, as was recognition of caring as an important and legitimate role. More flexible working patterns and reducing the career disadvantages associated with part-time working were also seen as important.
- **7.** The need to promote early and proactive preventative support for carers was endorsed.

Which suggestions can be derived out of this initiative for future actions / steps?

Based on the results of the REACT phase, an overview / summary of the key findings from NASURE and the REACT discussions is being produced and this is to be circulated to participants from the REACT events so that they can comment and the summary be amended accordingly.

2.7 European Level (AGE and other partners)

EUROPEAN LEVEL					
Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
2005-10-12 **Brussels**	AGE Platform In co-operation with the bureau of Anna Zaborska (MEP)	Working dinner in the European Parliament	Policy makers at the European level	**Presentation of the EUROFAMCARE Project** on Family Care of Older People in Europe in **European Parliament**	▪ Welcome (A. Zaborska) ▪ Brief introduction to the EUROFAMCARE project (H. Döhner) ▪ Objectives of the working dinner (A.-S. Parent) ▪ Presentation of the project findings and recommendations on policy and practice (J. Triantafillou) ▪ Debate, discussion and response of policy-makers and policy stakeholders to the findings and recommendations on policy and practice ▪ Conclusions and thanks
2005-12-06 **Brussels**	AGE Platform In co-operation with the bureau of Anna Zaborska (MEP)	Seminar in the European Parliament	Policy makers at the European level	**Presentation of the EUROFAMCARE Project** on Family Care of Older People in Europe in **European Parliament**	▪ Introduction to the EUROFAMCARE project (H. Döhner) ▪ European Union Policy Context (AGE) ▪ Family Care in Europe (M. Nolan) ▪ Pan-European Background Report on Family Care (E. Mestheneos) ▪ Family Carers and use of Services, (B. Krevers, G. Lamura, B. Wojszel) ▪ Labour Market issues, including the situation of migrant care workers (H. Rothgang, G. Lamura) ▪ Summary of the key messages of the EUROFAMCARE project (H. Rothgang) ▪ Panel reaction to the conclusions and policy recommendation of the project: Reactions from the European Parliament, European Commission, and NGOs (tbc)

EUROPEAN LEVEL					
Date + location	**Organiser**	**Kind of Event**	**Target group**	**Name of the Event**	**Title of Presentation**
2005-11-26 Paris	NOVARTIS France	Colloquium in the National Assembly of France	Policy makers on the national level (France)	**“Proximology” Conference on “Care-giving in Europe”**	▪ Döhner H., "Family Care for Dependent People in Germany: Current Situation and Legislation" ▪ Lamura G. & Melchiorre, M. G., "The situation of family carers of older people in Italy" ▪ Bien, B. & Bledowski, P., ”Specifities of the family care-giving for the older people in Poland – legal aspects of care” ▪ Johannson L., “The legal situation of family cares of older people in Sweden” ▪ Discussion with the auditorium
Not mentioned here: Publications / press releases / other mainly scientific presentations as well as presentations on European level (as described in the final report in the part “Exploitation and dissemination activities”)					

Overview of the REACT activities performed on European level in 2005

EUROFAMCARE	**Research Action (REACT) activity AGE I**
Country	Belgium (AGE Platform)
Data of the event	2005-10-12
Location	Brussels
Duration	3 hours
Kind of the event	Working dinner
Name of the event	Presentation of the EUROFAMCARE Project on Family Care of Older People in Europe in European Parliament
Number of participants	24
Target groups	Policy makers at the European level
Program	It was a working dinner organised at the European Parliament

Structure of presentations

- Welcome (A. Zaborska)
- Brief introduction to the EUROFAMCARE project (H. Döhner)
- Objectives of the working dinner (A.-S. Parent)
- Presentation of the project findings and recommendations on policy and practice (J. Triantafillou)
- Debate, discussion and response of policy-makers and policy stakeholders to the findings and recommendations on policy and practice
- Conclusions and thanks (A. Zaborska, A.-S. Parent, H. Döhner)

It was an opportunity for policy-makers to respond to the project findings and conclusions and the policy process. The policy responses received will help to identify future actions on visibility, lobbying and inform the planning of the event [2] in December in Brussels.

EUROFAMCARE	**Research Action (REACT) activity AGE II**
Country	Belgium (AGE Platform)
Data of the event	2005-12-06
Location	Brussels
Duration	3 hours
Kind of the event	seminar
Name of the event	Presentation of the EUROFAMCARE Project on Family Care of Older People in Europe in European Parliament
Number of participants	60
Target groups	Policy makers at the European level
Program	It was a meeting organised at the European Parliament

Structure of presentations

- Introduction to the EUROFAMCARE project (Hanneli Döhner)
- European Union Policy Context (AGE)
- Family Care in Europe (Mike Nolan)
- Pan-European Background Report on Family Care (Elizabeth Mestheneos)
- Family Carers and use of Services (Barbro Krevers, Giovanni Lamura and Beata Wojszel)
- Labour Market issues, including the situation of migrant care workers (Heinz Rothgang and Giovanni Lamura)
- Summary of the key messages of the EUROFAMCARE project (Heinz Rothgang)
- Panel reaction to the conclusions and policy recommendation of the project: Reactions from the European Parliament, European Commission, and NGOs
- Debate

2.8 EUROPEAN UNION (AGE – with participation of members of Consortium)

Overview of the REACT activities performed in 2005

EUROFAMCARE	**Research Action (REACT) activity EU I**
Country	(Greece) EU
Data of the event	2005-06-20
Location	Brussels
Duration	25 minutes
Kind of the event	AGE Platform Council Meeting
Name of the event	Presentation of work to Council
Number of participants	30+
Target groups	Service providers; older people's organisations
Special guests	These were elected representatives for their country. Each comes from an organization of older people or, in some cases, from NGOS or associations providing services.
Programme	Executive Meeting (3 times per year)

What are the specific aims of this initiative / action?

To inform the AGE Platform members of developments in research and policy.

Which methods are we using by means of this initiative / action to reach the above aims?

A presentation was made with Jyostna Patel from AGE, of the EUROFAMCARE research, specifically the PEUBARE report.

What are the expected results from this initiative / action?

Information – this has also been printed in the newsletter of AGE – and the desire to disseminate the findings to the 25 MS – most of whom have a representative on the Executive Council.

(Afterwards) **What are the actually achieved results?**

Not known (at a subsequent Executive meeting 2 people said they had downloaded and read PEUBARE and enjoyed it, and found it useful).

Which suggestions can be derived out of this initiative for future actions / steps?

A further presentation will be made to Executive Council in the next June meeting. Consideration will be given to producing a flyer for the AGE AGM in April 2006.

EUROFAMCARE	**Research Action (REACT) activity EU II**
Country	(Greece) EU
Data of the event	2005-06-29
Location	Brussels, European Parliament
Duration	2 hours
Kind of the event	InterGroup on AGE Meeting on the impact of ageing on Demographic Change in the EU
Name of the event	Presentations on recent research and implications
Number of participants	60+
Target groups	Commission officials, policy stakeholders on ageing and demographic change
Special guests	Parliamentarians
Programme	Presentation of selected findings from EFC- PEUBARE in context of policy for older people

What are the specific aims of this initiative / action?

Information for MEPs and Commission on the impact of demographic on different groups in society such as women, youth and family carers.

Which methods are we using by means of this initiative / action to reach the above aims?

AGE has the Secretariat for the Intergroup on Ageing and is responsible for arranging meetings to inform MEPs on policy priorities on ageing.

What are the expected results from this initiative / action?

To raise awareness on demographic change and its impact on older people.

(Afterwards) **What are the actually achieved results?**

The Intergroup meeting, at which the then head of the Commission's Social Protection Unit, gave a presentation, aimed to make visible to MEPs the reaction of policy stakeholders to the priorities identified by the Commission in the Green Paper on Demographic Change.

The conclusions of the meeting were also included in AGE's contribution to the Green Paper. The presentation on the PEUBARE to make visible the situation of family carers in the context of demographic change.

EUROFAMCARE	**Research Action (REACT) activity EU III**
Country	(Greece) EU
Data of the event	2005-10-12
Location	European Parliament, Brussels
Duration	3 hours
Kind of the event	Dinner for selected MEPs
Name of the event	Presentation of EFC and specifically PEUBARE results
Number of participants	20
Special guests	Parliamentarians and their aides, the Commission, including a representative of Commissioner Spidla’s cabinet.

What are the specific aims of this initiative / action?

AGE arranged a dinner so the issues of family care, as learned from the PEUBARE, could be presented to interested MEPS in an informal setting. Representatives from the Commission also attended.

Which methods are we using by means of this initiative / action to reach the above aims?

Careful presentations through the dinner of selected items from PEUBARE where policy action was needed.

What are the expected results from this initiative / action?

Influence EP and EC.

(Afterwards) **What are the actually achieved results?**

This and other activities have influenced the Commission to put FCs on the reporting Agenda.

EUROFAMCARE	**Research Action (REACT) activity EU IV**
Country	(Greece) EU
Data of the event	2005-12-06
Location	Brussels, European Parliament
Duration	2 hours
Kind of the event	Seminar on Family Carers organised by AGE
Name of the event	Presentation of EFC
Number of participants	50
Target groups	Caregivers’ organisations, others
Special guests	Parliamentarians and associates, European Commission
Programme	See above

What are the specific aims of this initiative / action?

Since the final conference was held in Hamburg, the aim of this event was to present to policymakers in Brussels the results of the EUROFAMCARE project.

Which methods are we using by means of this initiative / action to reach the above aims?

Presentations were made by the core partners on the main conclusions of the project and also included a summary of ‘key messages’ on the situation of family carers.

What are the expected results from this initiative / action?

To raise awareness on the situation and trends on family care in the EU.

(Afterwards) **What are the actually achieved results?**

The Commission’s Social Protection Unit has a requested a summary by member state on family carers, which will be used to draft questions on health and long-term care priorities.

Which suggestions can be derived out of this initiative for future actions / steps?

Informally, Mrs Zaborska’s office has suggested that the European Parliament’s Committee on Women’s Rights and Gender Equality could propose an own initiative report on family carers.

EUROFAMCARE	**Research Action (REACT) activity EU V**
Country	(Greece) EU
Data of the event	20th October 2005
Location	Brussels, European Parliament
Duration	2 hours
Kind of the event	InterGroup on AGE Meeting on Long Term Care
Name of the event	Older People and priorities for Long term care in the EU
Number of participants	80
Target groups	Service providers; elderly' organisations; caregivers' organisations, health authorities; social care authorities; researchers; others
Special guests	Commissioner Spidla, the European Parliament rapporteur on health and long term care, a representative of the WHO
What are the specific aims of this initiative / action? The aim of this initiative was to focus on the re-launch of the OMC on health and long term care **Which methods are we using by means of this initiative / action to reach the above aims?** This event provided an opportunity for a member of the project to give information on issues and trends on family care in the EU. **What are the expected results from this initiative / action?** To ask the Commission for information on progress on the OMC on health and long-term care (Afterwards) **What are the actually achieved results?** Commissioner Spidla in his speech informed the meeting of the timetable on the launch of the OMC referred to above. The MEP who hosted this meeting said it was one of the best meetings he had chaired.	

3 Summary

Depending on the specific situation of the country and resources available every partner decided what kinds of activities to conduct. All countries team members took part in different events attended by policy makers and care service providers, presenting EUROFAMCARE project results (local, national and international conferences / congresses, workshops, seminars). Some countries organized workshops with participation of local and national policy makers, service providers and professionals working on the field of geriatrics, gerontology and nursing as well as NGO’s representatives. In some of them representatives from countries not directly involved in the EUROFAMCARE project participated (Lithuanian representatives in the workshop conducted in Poland and Spanish representatives in the workshop conducted in Italy). Contacts established with a network of service providers and privileged witnesses – public and private service providers, elderly and caregivers’ organisations, health and social care authorities allowed collecting and evaluating the network members’ interpretations of and reactions to the survey results, especially in cases of controversial or critical aspects identified by them. Contacts established with the NG Organisations would allow to planning possible common activities to raise awareness on the issue of family carers among policy makers and service providers, especially in those countries where the family carer’s role is not recognised. A few events were also organised on the European level: a working dinner and a seminar in the European Parliament, Brussels, and a seminar at National Meeting in the French Parliament, Paris. Project results presentation to members of EU Parliament was an opportunity for policy-makers on European level to respond to the project findings and conclusions and the policy process. The deliverables of REACT are reflecting the results of the projects as well as the discussions conducted with various target groups on different levels.

The REACT phase is not finished – partners are planning their participation in other events allowing them to disseminate the project results and contributing to an “active” change of attitudes amongst health and social care system actors towards the partnership approach in family care.

4 Deliverables

4.1 Germany

Aim

The aim of work package 15: Research Action – REACT within the framework of the project EUROFAMCARE was to discuss the results of the different partial studies with experts having practical experience and with family carers, in order to formulate proposals to improve existing offers for persons in need of care and their relatives or to stimulate new approaches. It was planned to develop a manual for family carers and professional services based on the results of the REACT phase (deliverables 23 und 24).

Implementation of discussion events

During the REACT phase in Germany, the results of the project have been discussed with very different target groups. Besides discussions with other scientists, the target groups mainly consisted of experts of geriatric nursing practice (such as consultants for health and nursing services, managers and managing personnel of old people's welfare institutions, as well as politicians, representatives of outpatient services and other geriatric nursing staff) but also of family carers themselves. The presentation of the results and the focus of the discussions were adapted to the respective target group. Each event set off lively discussions with the participants that were taken down and summarised subsequently. These meetings mainly confirmed the results of EUROFAMCARE.

Main results of the interviews conducted with family carers

A main result of EUROFAMCARE in Germany is that, on the one hand, carers complain about a lack of support but, on the other hand, existing offers of health, care and social services are rather rarely utilised. Many offers claimed by family carers already exist. But the carers do not utilise them because they are not appropriate for their situation or because, in many cases, they never heard of them, as following statement shows:[1]

> *„1) Comprehensive information and counselling should be available for the relatives of old people (and not only in fat contradictory brochures) – With respect to: care (at home / nursing home) – financial and inheritance issues – provisions / power of authority – (all three in the form of check lists if possible). 2) Advice related to coping / understanding / dealing with the mental changes in old people and their behavioural patterns. 3) Access to quality checks of nursing homes. 4) More information on help for dying people in general and with respect to the different nursing homes. That is the only way to help our relatives adequately and also to be prepared for our own old age.“ (1072)*

All offers claimed by this relative already exist, but they are hardly known and rarely used.

The following lists the wishes of relatives ascertained by EUROFAMCARE:

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[1] All quotations come from the open part of the NASUR questionnaire for Germany. The numbers refer to the identification number of the questionnaire.

Better information on relief offers and clinical picture

Family carers mainly complain about a great lack of information. The study results show that in answer to the question which are the most important supports for family carers, they selected, out of 14 possible answers, the two items related to information, which ranked first and second. Family carers most often miss “information and advice concerning the available help and support, and how to access them“:

> *„(…) I was surprised when I saw that the sheet itemised an offer for advice and support of family carers. I have never been informed about that. Why not? In my opinion, long-term nursing insurances should also establish contact with the carers. (…)“ (3050)*
>
> *„It is regrettable that perhaps or even certainly, one does not know about all the possibilities that one could utilise to get a little bit more relief. (…)“ (1145)*

The wish of carers ranking second concerns „information on the illness of the person in need of care“, i.e. the clinical picture und the course of illness. Quotations from the open part of the questionnaire vividly support this result:

> *„I would like more support concerning questions of aging: what is normal, what is pathological. Support by geriatrically trained persons is inadequate. Many offers like self-help groups are scarce. GPs (at least many of them) are not able or not willing to be concerned with these questions. They just tell you "You have to consider the age." But what and how is age!” (1131)*

The discrepancy between perceived needs of family carers und the low degree of utilisation of existing offers of the health, care and social services was a central matter of concern for the suppliers of services in all discussion groups and corresponds to their experience. They feel that they are already producing a great amount of information, but apparently are not able to reach their target group. There really exist offers for many of the wishes expressed by the relatives. But the relatives lack the necessary information about these offers or the access barriers are too high.

Possibilities of relief time from care giving

With respect to concrete help, the possibility to have rest and time off from caring is of major importance for family carers, particularly if the person in need of care lives in their home. The quotations and group discussions show that here, too, there is a lack of knowledge concerning concrete offers and financing possibilities.

> *„(…) It should be possible to get help at short notice. (…)“ (1028)*
>
> *„I would like discussion groups for relatives with simultaneous caretaking of the person in need of care. A great many care related groups are offered for family carers, but after 16 years of care giving, that is no longer of interest to me. If the partner is no longer able to talk and friends and neighbours therefore withdraw from you, the need for conversation is very strong.“ (1067)*

In the open questions, in addition to the financial burdens, the time and energy consuming bureaucratic procedures related to applications has been criticised very often. Relatives would like *„less bureaucracy related to the decisions about applications“. (5113)*

> *„Confusion for patients and their relatives: What is covered by which insurance? Health insurance or long-term care insurance? What is the use of quoting SGB XI in officialese! In case of rejection e.g. reference to the social security office, but no reference to*

> *'benefits of the long-term care insurance'." (1116) „(…) it was a constant battle for the care level or for possible support. (…)"*

Compatibility of care and gainful employment

Family carers, who are (still) employed, stated in the questionnaire that a better compatibility of care and employment is a matter of great concern for them. This requires on the one hand a greater flexibility of the labour market and on the other hand, more offers for the care needing person so that the family carer could be absent for several hours. None of these requirements hardly ever exist in Germany and thus, care potential is either lost, or the caregivers neglect their own security in favour of care giving.

> *„(…). I am now 46 years old and have a family of 2 children, 12 and 13 years old. Both parents-in-law became ill at an early age, brain tumor, stroke. We were able to organise their care without government help. But I had not sufficient strength to take up my former profession in addition." (2004)*
>
> *„(…) My mother has been living with me since 22 years, because she gets only a small pension. But after the death of my husband and giving up my profession to take care of her, I have hardly enough to live on. I cannot afford help." (5784)*

In the discussion events with relatives, the high significance of the profession as a relief from care giving was often mentioned. For many caregivers, the profession is the only possibility to be in contact with other people and other topics and to "get away" from the care situation.

Possibilities of interchange with other persons

Approximately 78 % of all interviewees in Germany do not utilise any of the specific relief offers for family carers. Only 6.5 % take part in a carers' group or self-help group, although the interviewees, according to their own statements, attached great importance to contacts that offered opportunities of exchange about the care situation. Many interviewees stated that they could talk to members of their own family so that carers' groups have little importance for them. Those family carers, however, who took part in carers' groups, most often commented on them in a very positive way.

> *„I can only advise family carers to visit discussion groups for family carers. It is a relief to get everything off one's chest, because nobody in my own surroundings has enough patience for that. (…)" (1045)*
>
> *„Experiences: Care societies, self-help groups, discussion groups for relatives are indispensable for family carers. They offer the opportunity to freely talk about topics that one would not even mention to relatives. (…)" (1023)*

The discussion events with relatives confirmed that caregivers bear an enormous burden, that they have a great need for sympathetic listeners and that this need is rarely fulfilled in everyday life outside carers' groups.

Wish for appreciation and esteem

The discussions and the analysis of the open questions clearly showed how much relatives suffer from the low degree of recognition and appreciation they receive for their work both by the general public (and also by their friends and families) and by the professional services. *„The achievements of private carers should receive much more public appreciation.“ (5115)*

> *„When filling in the questionnaire, I clearly recognise what is that I miss and that would help me to endure or relieve care giving and all the strains related to it: It is the social appreciation. Appreciation for accepting to take on responsibility for old (sick) people and be therefore restricted in one' own life. (…)" (1005)*

> *„Since about 1 year, I have been suffering from severe depression. Since about 6 years, I have been supporting my parents for approximately 12 hours per week. (…) The worst for me was the lack of appreciation from society!! And financial losses for not being gainfully employed!“ (2004)*

This critique is also directed towards the procedures of the long-term care insurance when assessing care levels:

> *„My proposal: The medical review board should be much more emphatic in their relations with relatives. I always get the feeling that I apply for benefits that are not justified.“ (3044)*

To summarise the results of the discussion events, representatives of services mainly focused on the discrepancy between offers and the lack of utilisation and were interested in potential gaps in the range of services, while in the discussion with relatives, the emphasis was rather on the wish for greater appreciation.

Financial support

Mainly in the open questions, family carers expressed their lack of understanding for the fact that benefits in kind by professional services are remunerated so much higher than their own care commitment. The lack of financial means is a recurring complaint.

> *„Home care should receive greater support. The medical review board proposed that I should place my mother in a nursing home. The costs for the long-term care insurance would be about 1000,- Euro higher. If I keep her at home, they were not willing to pay me the additional 250,-Euro. I don't understand it. It would be a relief for me.“ (5784)*

In the REACT meetings, financial topics were only a marginal issue.

Not be at the mercy of fate

The discussion event with family carers revealed that their own situation is assessed positively by those who do not feel at the mercy of their fate but feel that they have an influence on their situation and can achieve an effect. This was mainly true for relatives who were involved in self-help organisations.

One reason, why carers do not accept offers specially conceived for them, is due to the fact that they do not recognise that they are meant when "family carers" are addressed. They see themselves as caring, nursing, someone who takes care of a family member as a matter of course, but not as a "family carer".

> *„Family carers often have to overcome a high threshold before they apply for a constant attendance allowance, as the help and initial care they give to their family member is seen as a matter of course from both sides. (…)“ (5657)*

The issue of how to address the target group and what concepts to use gave rise to discussions among the providers concerning alternatives. Although no convincing solution was found, they acknowledged that this problem needed attention because it might be the reason for the low degree of utilisation of their offers.

Summary

Family carers complain about an enormous deficiency of information, in particular related to available support offers but also related to the illness of the elder person and the further course of the illness. They would like to have appropriate offers that enable them to take time off from care giving. Moreover, many relatives suffer from the lack of appreciation and recognition of their work by the society, but also by their families and the providers of services. Relatives think that an interchange with other persons is very important, but only few of them are involved in relatives' groups. Many offers are felt to be too expensive, the bureaucratic procedure is a barrier, and the compatibility of care and employment often reaches limits that cause many women to give up their employment. And last not least, it is often difficult to reach the relatives, because they do not see themselves as "family carers".

On the other hand, the providers of services in the health, care and social sectors are very interested in reducing the deficiency of information, in closing gaps in the care giving system and providing appropriate support for family carers, but they often do not have access to the target group. The profusion of widespread information material (brochures, guides, flyers, journals, internet, information events, etc.) reaches the target group rarely or too late, and existing offers are often hardly utilised. There is a certain helplessness regarding the decision which alternative procedures should be developed.

Conclusions: Organisation for family carers

Situation in Germany

> *„(…) I hope that the survey helps to establish a kind of "competence community" based on the relatives' experience. (…)" (4028)*

An important result of the REACT phase in Germany is the awareness that the conventional way of imparting information apparently does not reach the target group or reaches it too late, i.e. it is not successful. The discussion events showed that family carers do not need another written guide. Therefore, the German project group decided not to produce a written guide for relatives, as had been the intention at the start of the project. Based on the project results, other priorities were chosen, because they promised greater success and a better response to the family carers' needs of appreciation and support.

> *„We would like to have a place, where relatives are advised in a competent and thorough way, where they might be relieved of activities and correspondence, e.g. district court, obtaining care products, etc. (…) These possibilities / contact points, which might partly even exist, would have to be much more widely known." (4017)*

We propose to found a national organisation for family carers in Germany. So far, there was no German-wide organisation of this kind. There exist mostly self-help initiatives for particular clinical picture, e.g. the Alzheimer association or the brain league, where carers are involved, and meanwhile there are a few regional relatives' initiatives. But what is really required is a

German-wide initiative that would bring together the existing regional associations and would stimulate new ones; they should all have the same name and telephone number – comparable to the police and emergency doctors – and they should be able to represent the interests of carers also on the political level.

Models of good practice in Europe

The idea to found an organisation for family carers is based upon the examples of some of our partner countries. The 23 NABARES and six NASURES of EUROFAMCARE made possible a hitherto unique comparison between the situations of family carers in different European countries and thus identify examples of good practice, which have been compiled in a special project document.

Moreover, in connection with the foundation of the European relatives' organisation „EUROCARERS – European Association Working for Carers" and the design and development of the "European Carers Charter" (cf. report ad WP16) we got to know very different national and regional organisations for family carers all over Europe and could observe their positive effects on the carers, but also on the society as a whole. The countries, which already had experience of national organisations, could provide many suggestions for the European initiatives. On the other hand, it is hoped that the activities on the European level will motivate all countries to develop national activities.

In the meantime, we designed a questionnaire that was sent to European countries such as Ireland, Scotland, UK, Sweden, Finland, The Netherlands, Belgium, France and Malta (in foundation), which had founded national organisation for family carers in the last years. The evaluation shows that the main concern of all these organisations is the political representation of the interests of family carers on the national level, e.g. better compatibility of care and employment and raised public recognition and appreciation of family carers. On the regional level, the organisations are concerned with concrete support for the relatives, showing them that they are not alone, finding new ways, informing them of possible relief services and possibilities of interchange with other carers. The standardisation of the name and telephone number for all relatives' organisations in a country helps the carers to know without delay where to turn to in case of need. This might help to reduce the big problem of access.

It has been shown that in countries, where national organisations existed since several years, public awareness changed. The concerns of caregivers became more visible. Politics reacted by the enactment of various laws. The organisations initiated "National days of family carers" and "Charters for family carers", which contributed to draw attention to the situation and needs of caregivers, and thus contribute to change the self-awareness of the relatives. However, sponsorship, structure and mode of financing of the organisations for family carers considerably differ between the individual countries. Some organisations were founded on the initiative of relatives, others with government help, others as an umbrella organisation of existing local relatives' organisations. But in all countries the structure is similar, viz. an umbrella organisation, which is mainly concerned with lobbying on the political-social level, and many regional associations, which are low-threshold contact points for family carers and assume tasks related to information and advice on the location. All regional contact points that belong to the organisation **have the same name countrywide** and are therefore publicly known and recognisable.

On the one hand, a national organisation that represents the interests of family carers is able to pool the wishes and suggestions of carers in such a way that providers can react in an appropriate way. It is able to lobby on behalf of the family carers on the political level and for instance campaign for a better compatibility of care and gainful employment. It can contribute to family carers receiving more public regard and appreciation.

On the other hand, an organisation for / of family carers can contribute to change the self-awareness of family carers and facilitate their access to information and thereby to the utilisation of services. According to our study results, only every fifth family carer takes advantage of relief offers for himself / herself, which has to be understood as a social warning signal. Caregivers have a strong tendency to expect too much of themselves, to neglect their own interests in favour of their care needing relatives. This involves a higher risk of falling ill and needing care themselves.

It would be very useful, if an organisation known under the same name all over Germany were also represented online by an electronic advice platform that would provide information on national and regional offers. Preliminary work has already been done.

The next steps

In order to detect which type of organisation is appropriate for the German situation, we plan to carry out a workshop with representatives of various interests groups in order to discuss necessities, aims, tasks and possible sponsorship. A letter has already been sent to the Ministry for family, women, seniors and youth, asking for their support.

We have already pointed out that an organisation for family carers in Germany does in no way intend to compete with existing self-help organisations that focus on certain groups of illness. The object is rather to combine the forces of many dedicated people to better represent the interests of directly or indirectly affected families with members, who need care or nursing. The initiative is not only meant for relatives who take care of elder family members (who were the target group of our project), but for all those, who take care of a close person in an informal way. Parents of children in need of care belong to the target group as well as care giving friends or neighbours. It also includes children or adolescents, who take care of a parent. In contrast to e.g. the United Kingdom, the situation of these children and adolescents has hardly reached public awareness in Germany, though their need for support is enormous.

Existing self-help organisation could be possible cooperation partners, like the Alzheimer associations, the brain league, the stroke help, the rheumatics' league, associations of parents of sick children and relatives of mentally ill persons, various regional relatives' initiatives, but also the federal working committee of information centres for relatives – BAGA, etc.

Unlike any written guide for carers and service providers, an organisation for family carers is much better able to draw public awareness to the discrepancy between felt needs of family carers and the low degree of utilisation of existing offers of the health, care and social services and to increase the efficiency of new approaches. Carers will thus be able to have a low-threshold access to important information and advice. Care providers will be able to assess the needs of relatives and possible gaps of care services. It is the only way to do effective lobbying on the political level. The foundation of an organisation for family carers is therefore of major importance in the field of social politics.

4.2 Italy

On the background of the findings emerged from the analysis of the collected data, and their interpretation in collaboration with representatives of family carers' organizations, service providers and policy makers, following recommendations can be formulated with regard to the Italian context.

Support services by family carers

Compared to other countries where an articulated network of "formal" support services for family carers is already available, Italy shows a situation which needs more systematic measures to enable current service providers to deliver not only focussed information for carers on how to properly deal with the care-giving situation, but also more respite as well as socio-emotional care services (such as for instance counselling, social work or self-help groups). This is necessary in order to unburden more traditional "generic" services, i.e. services not created to specifically address family carers' needs, but which currently play a substitution role in relieving and sustaining family carers in their everyday tasks. General Practitioners, in particular, are key figures in this respect, and should be better networked – at an informational and organizational level – with existing services for the acute or long term care, thus ensuring a higher and much needed care continuity.

Care allowances and employment of migrant care workers

Differently from other countries, in Italy one of the main means to provide support to dependent older people is represented by care allowances (i.e. direct payments), allocated by local or national public authorities to the recipients so that these can cover, at least partly, the (effective or figurative) costs of the help received by (private or informal) care providers. Policy makers should therefore consider that, to grant a better recognition of the major role played by family carers in Italy, the above allowances – which are paid to the older person – could be usefully integrated by (or split into) monetary payments directly to the carer, possibly accompanied by pension benefits related to the time spent in providing care-giving tasks. In case these allowances (no matter whether paid to the family carer or the older person) are used to pay a home care worker – a more and more widespread solution in Italy thanks to the availability of "low cost" foreign migrant care workers, often on a cohabiting basis – it would be necessary to couple them with an accreditation system of such workers, in order to prevent undeclared work and at the same time better qualify the care work provided by such care staff.

Carers' experience in using services

A first aspect regarding family carers' experience in using support services is their cost. Empirical evidence emerging from the EUROFAMCARE study reveals that most of the few services available are usually delivered for free or with a low contribution from the recipients, being most of them funded through public agencies. However, in Italy the demand for some kinds of support services – especially for socio-emotional support – is higher than their public supply, so that family carers see themselves sometimes compelled to pay private providers to receive them. The overall paid amount remains however, apart from few exceptions, quite low on average (only one out of ten paying carers spends more than 20 Euros per month).

This suggests that more services providing socio-emotional support for carers should be developed and offered by public agencies in Italy, covering areas that are currently completely lacking them.

Overall satisfaction about the capacity of the few used services to meet carers' needs is on average quite high in Italy, with lower levels being recorded only for the assessment of caring situation. In this respecting, a more regular, multidimensional monitoring of the carer's conditions is probably an inevitable solution in order to grant a more focussed support to heavily burdened carers.

A further area on which improvements are needed in Italy is represented by the accessibility of care and support services. Health care professionals are the main "gate-keepers" of the care system in Italy, while social services seem to play – at least in the family carers' eyes – a more marginal role. In this respect, it is certainly a priority to advocate a higher integration between the two sectors, on the one hand, and between them and the informal sector (family, friends and neighbours), on the other hand, that in Mediterranean countries like Italy is particularly relevant.

Major obstacles in accessing services and support are identified by Italian carers mainly in the bureaucracy and complicated procedures needed to be able to use them, in the lack of information and in the existence of long waiting lists. Less relevant - but still widespread enough to justify active engagement from policy makers and service providers to reduce their negative impact on (potential and current) users - are aspects such as the high costs of services, their poor quality and their distance or lack of adequate transportation to reach them. High costs and lack of adequate information prove to be the major reasons for not using needed but never used services in countries – like Italy – characterized by a generally lower economic and educational level of their older population. The clear message deriving from such a situation is that there is a high need in Italy for systematic measures aimed at improving the ability of the care system to properly inform citizens about available opportunities, but at the same time enabling them to take advantage of such opportunities irrespective of their economic conditions, thus allowing for possible income redistribution effects aimed at ensuring a more universal service accessibility.

Carers' preferences for support types and services characteristics

Italian providers should (re)formulate the range of care and support services (to be) provided, by taking more into account the preferences manifested by family carers. In this respect, it should be underlined that information and advice about the disease suffered by the older person as well as on how to access available services are on the top of carers' list of preferences, followed by the "opportunity by the older person to undertake activities they enjoy", holiday or care break opportunities for carers, including the possibility to spend more time with the family, as well as to better combine care-giving and paid employment. Less relevant are carer support groups, training opportunities and the possibility to talk about problems or deal with family disagreements.

This reorganization and development of current services should also consider whether – and to which extent – expressed preferences are currently being met or not. In this respect Italy shows a situation in which virtually all types of support currently provided to family carers can be judged as insufficient, since they reach only part of those considering them important. All in all, the most unmet type of support is financial help, followed by information on access to existing services. A similar situation emerges with regard to the most relevant service characteristics. Those more often considered as “very important” by carers are overall the necessity that “care workers treat the older person with dignity and respect”, the ability of the service to “improve the quality of life of the older person”, as well as its timeliness, and that “care workers have the skills and training they require”. Less important are services that “fit in with carers own routines”, are provided by the same care worker or consider carers’ needs, quality of life and opinion, revealing quite clearly that the most relevant worry for family carers concerns the quality of the treatment reserved to the older person, and not to themselves. The question on how such preferences are currently met by the actual service provision shows that in Italy services are mainly considered by carers as not being satisfactory especially with regard to their expensiveness and of their (un)timeliness, thus confirming the urgency of intervening to cut waiting lists and reducing economically derived inequalities in service access.

Service effectiveness

A final reflection proposed to policy makers and service providers regards the need to increase the effectiveness of provided services by intervening on the main determinants of the negative impact of caring on family carers. This is mainly associated with the characteristics and needs of the older person (depending on his / her health status and functional abilities but also living arrangements), the intensity of the caring tasks performed by the carer (in terms of hours of care provided per week), the strength of the carer’s support network and the type of services used. Particular attention should therefore be paid in ensuring high quality of those services – such as general hospital / acute care, home based domestic services, cohabiting non-family paid carer and emotional / psychological / social support services – which are mainly used by more frail elderly and, in this connection, by more burdened family carers.

4.3 Sweden

The Swedish Action plan

The future action plan is to write a Swedish report to be publicized in collaboration with The National Board of Health and Welfare presenting the most important results from the EUROFAMCARE project about the situation of family carers’ situation and service use. The report will be available for decision makers, service providers, family carers and others. In Sweden it is the authorities at different levels that are responsible for developing guidelines. This information will be possible to use together with other facts and considerations in the development of guidelines.

The following is a short summary of the empirical findings of the Swedish EUROFAMCARE project.

Summary of the Swedish EUROFAMCARE project

Introduction

The aim of the national survey report (NASURE) is to describe the situation of family carers of elderly people in the individual country in relation to the existence, familiarity, availability, use and acceptability of supporting services.

The EUROFAMCARE project is exploring the characteristics, coverage and usage of services supporting family carers and older people in Europe.

This summary describes the following part of the EUROFAMCARE project. At a trans-European level, studies of a core group consisting of six countries: Germany (co-ordination); Greece; Italy; Poland; Sweden and the UK, have been conducted studies to examine different care arrangements for older people and family carers. The main focus is on the perspective of family carers. Following a common study protocol the individual countries have conducted:

- A baseline survey study including interviews with approximately 1,000 family carers per country
- A one-year follow-up study with family carers from the baseline study that accepted to be contacted
- A service provider survey study including interviews with approximately 20-50 service providers

Method

The six-countries developed a common research protocol. The respondent should support an older person 65+ for at least 4 hours a week and / or organises the care provided by others.

A combination of national statistics of distribution of elderly, known level of dependent elderly and the expected number of carers in a population was used for planning of the sampling.

Three different geographically areas were chosen in Sweden based on urban and rural differences, geography and different models for service provision. The chosen areas were South West, Eastern and North of Sweden. In each region we calculated the expected number of family caregivers based on previous reports also including the expected number from urban and rural areas. The strategy for sampling was aimed to try to ensure that the sample would represent a variety of caring situations.

Family carers have been recruited through the agreed saturation method, which consists in contacting the universe of caregivers living in three chosen sample regions. The major mode used was personal contacts and in East of Sweden contacts by telephone using a random sample of the inhabitants in that region.

The initial strategy to collect participants did not give enough numbers in relation to the time-frame for the project and this led to changing the strategy by involving a subcontractor. The subcontractor did a collection by using phone numbers in the chosen areas and therefore a random procedure was used but on the other hand the saturation in each area cannot be guaranteed. This weakens the sampling method but the analysis of the collected material showed that it seems to be reasonable representative according to basic characteristics even if the geographical distribution is a bit skewed. The strength of the sample is that it gives the picture of the plurality of the caring situation from the carers perspective.

Even if the sampling gave some difficulties the sample is useful for description and comparison of different caring situations and a more in depth analysis allows for further comparisons between areas with different models for service distribution.

The common questionnaire, The Common Assessment Tool (CAT), involved a large number of questions about e.g. the older person's health and needs, the family carer's situation, and service use including costs. Mostly the same questions were used in the one year follow-up.

The service provider interviews were a complement to the interviews with family caregivers in order to elucidate service support also from a service provider perspective. A common questionnaire was used, the Service Providers Questionnaire (SPQ), which was standardised for use in all six countries. The geographical sampling for the service provider interviews followed that of the original sampling areas for the interviews with family caregivers, Southeast (SE), Southwest (SW), and North (N) of Sweden.

A theoretical sampling procedure was applied to include all relevant types of services offered to family carers and older people. The sampling framework allowed for interviews to be conducted with management representatives of different types of service providers in each area: public social and health service organisations, religious organisations, voluntary organisation and private / commercial organisations. The aim was to interview at least 5 service providers per area.

Potential responding organisations and respondents were identified through snowballing e.g. via co-ordinators and interviewers from the prior family caregiver interviews and through interviewed service providers. The data was collected by telephone interviews.

Characteristics of the sample

Nine hundred twenty-one family carers in Sweden were interviewed mostly by telephone.

The sample consists mainly of two large subgroups - those who are caring for their spouse and those who cares for a parent.

Over 80 percent of the older cared-for people still lives at home. More then half of the cared-for people in the Swedish sample are married or living together. Another large group consists of widowed people. Nearly 40 percent of the older cared-for people lives alone and approximately half of the cared-for lives with their partner.

Everyone in the Swedish sample receive pension or some other financial support from the state. A few people also receive some kind of allowance due to the caring situation.

The main reasons why people need care and support are; physical illness / disability, age-related decline and memory problems or cognitive impairment. Approximately half of the Swedish sample state that they suffer from memory problems according to the carers' perception. Over 40 percent of these people haven't yet got their problems diagnosed. About one-fourth of the cared-for people show signs of behavioural problems. About 45 percent doesn't suffer from neither memory nor behavioural problems, almost one-third of the cared-for people, suffer only of memory problems.

More than 70 percent of the cared-for people in the Swedish sample are moderately or severely dependent. over 90 percent, of the cared-for people partially or completely rely on others to handle is domestic needs. Over 80 percent of the cared-for people rely partially or completely on others to handle are; organising and managing care / support, financial management and emotional / psychological / social needs.

The mean age of the main carer is 65 years in the Swedish sample. There is significant difference between males and females mean age. The mean age of the male carers are four years higher then the females. Approximately 55 percent of the carers are 65 years or older. More than 70 percent of the main carers are females.

About two-thirds of the carers have at least an intermediate level of education of which approximately 37 percent have a high level of education.

Approximately one-third of the carers in the sample are employed. Almost 90 percent them are working in the private or public sector. About 14 percent of the employed carers have been forced to reduce their working hours due to the caring situation. There is just a small part of the non-working carers who cannot work at all or had to give up their work.

Eighty-five percent of the family carers are either married or cohabiting and 87 percent of the family carers have children and close to one-fifth of these have one child and about 48 percent have two children. The average number of people living in carers household, carer included, is two.

Almost half of the carers are the cared-for persons’ spouse or partner and just over 40 percent are the cared-for persons’ son or daughter. Ninety-six percent lives within a 30 minute drive or closer.

Approximately 70 percent of the family carers have been the main carer for more than two years. The average number of care-hours in the Swedish sample is 38 hours (median = 12 and std. deviation = ca 50 hours) so there is a large variation in the sample.

A small part, just under two percent, of the family carers receive some kind of allowance due to their caring situation.

Over 63 percent of the family carers estimate their health status to be “good” or better and about the same consider that their quality of life is "good" or better. The less hour of caregiving and the younger family carer the better health and quality of life. However the pattern is broken by those who consider they have poor health and very poor quality of life. About ten percent that caring have often have negative impact on their lives and most of the family carers consider that caring have positive value.

Different care situations

One of the aim in the EUROFAMCARE project is to show different care situations and the cluster analysis makes this possible. The distribution of clusters in the Swedish sample shows that cluster 3 (wives, high burden) is the most frequent care situation. It is to be noted that the distribution of the individual clusters in the countries does not necessarily represent the statistical distributions in these countries due to different recruiting strategies and representatives. The use of clusters allow – independent of the marginal distribution – the comparison of the care situation in the six countries.

The most frequent motive for family caring in Swedish sample is emotional ties as love and affection and caring makes the family carer to feel good. A large majority also consider that the state / society / public authority society should have main responsibility, and that family contribute, (this question was posed in the follow-up study). This might contribute to a situation in which people support their older people mostly by their free will.

Many of the family carers also consider it possible to let the older person live in a care home if they got worse, but only then, might reflect that they have strong emotional ties but also that they consider care home as a possible alternative.

Needs and service use

In this study the family carers provide the most support. Personal care is the most shared need domain that formal services also provide. Older persons' needs of financial and organisational management are mainly handled by family carers. Emotional, social and psychological needs are the domain that family carers support most and that is also a domain that they want more support for the older person.

Allowances are received just by a few persons and either not a highly requested type of support. This is not a great issue in Sweden since all Swedish inhabitants 65+ receive a pension and a high percentage of the women are in the labour market.

Family carers use a small amount of services due to their caring situation. Six percent use health care services and the most frequently used service specially designed to family carers are consultant, care attendant and relatives support group though each are use just by 5-6 %.

The most used health care services for older people are GP, technical aids, district nurse, chiropodist / podiatrist. These are used by 30-50 % during the last six month. The most used social services are transport services and tele-alarm system, used by 30-40 %. Some type of public social service that includes 2-5 of following services: personal care, food, cleaning, laundry, shopping are used by approximately 25 % of the older people. Day care is used by 10 %.

Social services and health care professionals are the greatest help to access service. Though about 50 % consider that more information about available support is needed. They also consider that information about older person's disease is the most important type of support, one third need more information about this.

The greatest difficulties that are specified in accessing services are besides lack of information, bureaucratic difficulties; few available services and poor quality. The dominate reason for those who did not use services were they did not needed any service, other reasons were social attitude by elder or carer; less frequent reasons were financial reasons and lack of trust in the service.

Family carers consider that used service mostly meet high values quality characteristics as that the older person shall be treated with dignity and respect by the care workers and that the help provided improves the quality of life of the older person. However one quarter perceive that the help is available at the time they need it most.

Service providers survey study

Totally 25 service providers were interviewed. The majority were head or manager for a service organisation, and most respondents were working in public social care organisations, one third was working with in public health care, just a few were service providers from the other sectors.

As the service providers' survey study mainly is a qualitative study the aim was to get as broad information as possible from those who have experiences from service support for family caregivers and older people and their relatives. However there are very few representatives from voluntary and religious organisations, which also reflect that there are less activities from these compared with municipalities and county councils. The same apply to private organisations and most of them are working on contracts from the municipality and have almost the same conditions as the purchasing organisation. With these limitations the study can be regarded to be trustworthy.

Questions that focus on quantitative aspects can just be seen as a pilot study and not representative for Sweden as a whole since it is a small sample. These are however interesting as a background information to the qualitative data.

There is a challenge to achieve flexible and individual service that fits different family carers' and older peoples' needs. There are some important issues:

One of the most crucial points is to develop a view among service providers and decision makers that emphasise that relatives have rights and needs in their own. If such view was more established it would probably lead to other actions. For this the national legislations are important as well as education, the latter is pointed out by the service providers themselves. Health care providers (most of them employed by the county councils) and social care providers (in the municipalities) are ruled by different laws. Compared to the county councils the municipalities have more special services and activities for family carers exclusively.

Even though service providers try to distribute information in a variety of ways there is still difficulties in reaching family carers. It seems as if personal contacts e.g. via health care or social care staffs is the best way to help individuals to identify themselves as family caregivers as well as to inform them about available services and to encourage them to ask for support.

The interviews also show a need for a more systematic and reliable approach on all levels concerning assessment of family carers needs and also evaluation of the effect and quality of services. That would give more reliable facts for decision making and development of services for family carers and older people.

There is also a need for more equal distribution of services, Sweden is a large country and many old people is also living in rural areas.

One-year follow-up study

One year later 575 family carers out of the 862 who had accept to participate in the follow-up answered a postal questionnaire.

The changes of the situation for family carers who still cares for an older person are small after one year. However the small changes who appear are significant in a deteriorated direction. In summary the situation is as follow:

Nine-teen percent of the older people have died and twelve percent has moved to institutional care. Both groups consist mostly of those with more severe dependency level.

More than one-third of the family carers that participated in the follow-up survey are for different reasons no longer the main carer. The cared-for person past away in approximately 53 percent of these cases.

The average number of hours of care per week has increased with nearly five hours. Nearly 45 percent of the carers have increased their number of hours of care per week. Family carers of those people who suffer from more severe IADL dependency had to increase their care-hours, while carers who take care of someone with low or moderate IADL dependency could decrease their care-hours.

Approximately one-third of the family carers are employed at the time of the follow-up, which is just a minor decrease compared to the first study. Ninety percent perceive their working restrictions in the same way as they did one year ago.

Almost one-third of the carer lack the possibility to take a break from the caring situation, the corresponding share at the time of the first study were about 23 percent. It is notable that 13 percent of those who easily could find a stand-in in the first study, now have no-one to turn to when it comes to taking a break.

The cared-for persons' level of IADL dependency has significantly got worse at the time of the follow-up. The family carers have also estimated the cared-for persons behavioural problems to be significantly worse. Furthermore almost 15 percent of the cared-for people who did not show any signs of memory problems in the first study, now show these signs. A positive change between the two point in time is the fact that a larger part of cared-for people now have had their memory problems diagnosed.

The result shows that the carers feel that their quality of life is significantly worse at the time of the follow-up than in the first study and the self-estimated health status is slightly worse. However, it is worth mentioning that the level of both quality of life and health status is fairly good. Approximately one-third of the carers report that their health status has gotten worse during the time between the two studies. The rest of the carers experience a similar or better health status.

The differences concerning their perception of positive values and negative impact of caring between the two points in time are not very large. However the result points in the same direction as earlier results, i.e. the family carers tend to estimate their caring situation slightly worse at the time of the follow-up. The positive value dimension shows that more than two-thirds of the main carers now appears to have a harder time coping with the caring situation. The negative impact dimension shows the same tendency, that a large part of the carers now feels that it is harder to cope with the caring situation. Almost 49 percent of the carers now feels that they have less support in their role as a carer then before. The rest of the group state that they have better or similar support.

4.4 Poland

Guidelines for service providers

One of the weaknesses of the supporting system for the family caregivers is the lack of full cooperation between service providers in field of medical care and social care and lack of good information for the NGO’s as well. Because service providers in the health care usually don’t know very much about the activities of the social care, the needs of elderly persons often remain unrecognized and not fulfilled.

The main task of Guidelines for the service providers is to point at such situations when elderly persons and their carers have the needs that often remain unnoticed by the people concentrated on their tasks in the field they already know well. The Guideline has a form of algorithm, followed by a short instruction explaining the importance of cooperation between both fields where the supporting for elderly persons and their family caregivers is needed. In the algorithm there are questions which provider should answer and then deicide in which area he should cooperate with the providers working in other fields.

Guidelines for family carers

In Poland, information connected with caring situations is still not popular and rather seldom available at public places. In our opinion each citizen should have an easy access to clear and simple information about caring process not only in clinics, information centres or social welfare offices, but almost everywhere – for example in malls or churches. Our brochure is an example of easy readable information called “A Path for Caregivers”, based on an American brochure for family caregivers (the text includes some EFC results too). The information is meant as a path which carers can go through answering themselves to some questions. These questions may help carers to recognize their own situation and can help them to find the way to share the care. The following questions and recommendations are simply stops on this path:

- Are you a caregiver?
- Why do people provide care at home?
- Are most family caregivers trained for the job they do?
- Do caregivers find the role easy?
- Is your family care-giving situation different?
- What are the greatest needs of family caregivers?
- Take care for yourself.
- Don’t try to handle all the care-giving responsibilities alone.
- Your needs as a family caregiver are being recognized and addressed.
- When to seek help?
- How to start getting the help you need?

At the end of this path a carer can find a list of various community resources which may help him care for himself and his family member or fiend.

Ścieżka dla opiekunów

(ma posłużyć jako podpowiedź odnośnie tego, jak podzielić się opieką)

Czy jesteś opiekunem?

Jesteś opiekunem, jeżeli w domu opiekujesz się przewlekle chorym lub potrzebującym innej pomocy starym członkiem rodziny lub przyjacielem / sąsiadem. Czas, który poświęcasz na opiekę może być zróżnicowany i wynosić od kilkudziesięciu minut do niemalże 24 godzin na dobę. Obowiązki, które wykonujesz, mogą między innymi polegać na myciu i ubieraniu kogoś bliskiego; gotowaniu, sprzątaniu i praniu; załatwianiu spraw finansowych; robieniu zastrzyków i podawaniu leków; zmianie opatrunków; załatwianiu sprawunków czy prowadzeniu spraw finansowych, oraz na tym, że stajesz się źródłem informacji zarówno dla osoby bliskiej, jak i członków rodziny.

Dlaczego ludzie sprawują opiekę w domu?

Opiekun może mieć wiele powodów, aby sprawować opiekę w domu. Najczęściej wymienianą przyczyną, która wpłynęła na decyzję, aby opiekować się osobą starszą, były więzy uczuciowe, takie jak miłość czy przywiązanie. Inne, chociaż rzadziej już podawane przyczyny opieki to zwykłe poczucie obowiązku czy też poczucie zobowiązania wobec osoby starszej jako członka rodziny. Zazwyczaj opiekę chcemy sprawować w domu, czyli w otoczeniu, które znamy. Ponadto, opieka w domy jest często jedynym rozwiązaniem, gdyż opieka prowadzona gdzieś na zewnątrz, np. w jakimś niepublicznym ośrodku pomocy, bywa zbyt kosztowna, jeżeli w ogóle jest dostępna. Niezależnie od motywacji, sprawowanie opieki domowej może dawać satysfakcję, ale może być również bardzo stresujące dla opiekuna.

Czy większość opiekunów rodzinnych jest przygotowana do pracy, która wykonuje?

Często nie, chociaż większość opiekunów uważa, że zazwyczaj bądź zawsze dobrze radzi sobie w pełnieniu roli opiekuna. Faktem jednak jest, że część opiekunów rodzinnych znalazła się w sytuacji opiekuńczej nagle i niespodziewanie i nasza wiedza na temat sprawowania opieki jest niewystarczająca. Oczywiście i ci opiekunowie starają się wykonywać swoje zadania najlepiej jak potrafią, polegając na doświadczeniu, intuicji i poradach innych osób. Jednakże to sprawowanie opieki nie musi przebiegać w sposób przypadkowy. Opiekunowie mogą nauczyć się od profesjonalistów i innych opiekunów tego, jak łatwiej radzić sobie ze swoimi obowiązkami, biorąc udział w specjalnych zajęciach środowiskowych czy spotkaniach grupowych, oraz z tzw. materiałów źródłowych, takich jak ulotki informacyjne czy poradniki.

Czy opiekunowie traktują swoje obowiązki jako coś łatwego?

Wielu opiekunów pełniąc swoją rolę odczuwa satysfakcję, ale tylko nieliczni zapewne powiedzą, że ta opieka jest łatwa. Z naszych badań wynika, że chociaż w odczuciu większości opiekunów sprawowanie opieki jest warte trudu, to jednak co trzeci opiekun przyznaje, że to pełnienie opieki stawia przed nimi zbyt wysokie wymagania. Warto mieć świadomość, że sprawowanie opieki może być fizycznie i emocjonalnie stresujące dla obu stron biorących w niej udział. Osoba starsza, kiedyś niezależna i dumna, może czuć się obecnie bezradna, może odczuwać złość, zmieszanie (zakłopotanie) czy strach. U opiekuna, presja wynikająca z istniejących obowiązków może przeplatać się z odczuciem niewystarczającego wymiaru świadczonej opieki czy niedostatecznego zapobiegania bólowi, z odczuwaniem zarówno miłości jak i litości do członka rodziny czy przyjaciela, czy odczuwaniem złości, że jakoś marnuje swoje życie ze względu na zaistniała sytuację.

Czy Twoja rodzinna sytuacja opiekuńcza różni się od innych?

Prawdopodobnie nie do tego stopnia, jak mógłbyś przypuszczać. Chociaż bez wątpienia Twoja sytuacja w jakiś sposób jest wyjątkowa, to inni opiekunowie mogli już wcześniej doświadczyć dylematów i odczuć, które Ty napotykasz dopiero obecnie. Zatem od profesjonalistów i innych opiekunów możesz dowiedzieć się więcej o chorobie lub niesprawnościach, z którymi boryka się bliska Ci osoba, o tym, jak radzić sobie ze stresem, jakie środki mogące ułatwić sprawowanie opieki są dostępne i jak zacząć planować swoją dalsze działania czy odleglejszą przyszłość.

Jakie są najistotniejsze potrzeby opiekunów rodzinnych?

Jako opiekun potrzebujesz pomocy (wsparcia) ze strony rodziny, przyjaciół, profesjonalistów i z lokalnych źródeł w okresie, w którym okresie, w którym ponosisz odpowiedzialność za sprawowanie opieki. Powinieneś wiedzieć, że nie jesteś sam. Ponadto miej świadomość, że po prostu potrzebujesz częstych przerw w sprawowaniu opieki, aby odnowić siły i zadbać o własne zdrowie. Takie przerwy mogą trwać tylko 10 minut dziennie, albo kilka godzin na tydzień, ale to musi być czas, który zarezerwujesz wyłącznie dla siebie. Zarówno Ty, jak i bliska osoba, którą wspierasz będzie mieć pożytek z tego, że wykorzystasz każdy rodzaj pomocy, który jest dostępny.

Dbaj o siebie.

Staraj się nie poświęcać swojego zdrowia w wymiarze fizycznym i psychicznym podczas wspomagania osoby bliskiej. Z naszych badań wynika, że co w przypadku 1 / 3 opiekunów sprawowanie opieki wywiera niekorzystny wpływ na ich zdrowie. Jeżeli zlekceważysz swoje własne potrzeby, prawdopodobnie przyspieszysz dzień, w którym Twoja pogorszona kondycja może zupełnie uniemożliwić Ci sprawowanie opieki. Jesteś winien to sobie i tej bliskiej osobie, którą się opiekujesz, że będziesz jadł(a) regularnie, wykonywał(a) ćwiczenia, i robił(a) od czasu do czasu przerwy w pełnieniu obowiązków opiekuńczych.

Nie staraj się podołać wszystkim obowiązkom opiekuńczym w pojedynkę.

Opieka, będąca często sama w sobie pełnoetatową pracą, stanowi zwykle dodatek do istniejących już obowiązków domowych czy tych związanych z pracą zawodową. Zbyt wielu opiekunów traktuje jako porażkę czy zaniedbanie sytuację, w której nie chcą lub nie mogą opiekować się kimś bliskim wyłącznie osobiście. Staraj się nie podchodzić do tego w taki sposób, bo rzadko zdarza się sytuacja, aby osoba starsza nie życzyłaby sobie tego, aby ktoś inny się nią również opiekował. A ponadto to nie realne, aby jedna osoba wiedziała wszystko i robiła wszystko sama w procesie opieki. To nic złego, jeżeli szukasz profesjonalnej pomocy lub szkolenia na temat tego, jak być lepszym opiekunem lub jak radzić sobie z własnymi emocjami. To nie jakieś zaniedbanie, jeżeli korzystasz z usług z zewnątrz, lub gdy przyznasz, że ta praca jest trudna czy nieprzyjemna, i że potrzebujesz wytchnienia od niej. W końcu to nie zupełne fiasko, jeżeli bliska Ci osoba będzie wymagała umieszczenia w szpitalu, czy domu opieki. Te różnorodne placówki pomocy, których jest też coraz więcej, wyglądają i funkcjonują dzisiaj znacznie lepiej, niż jeszcze kilka czy kilkanaście lat temu (jako dobry przykład można tu podać chociażby rodzinne domy pomocy dla ludzi starych). Zrób sobie listę zadań opiekuńczych, którym możesz podołać. Potem poszukaj pomocy wśród członków rodziny czy przyjaciół, lub ze strony sieci organizacji świadczących usługi dla ludzi starych, np. do takich zadań, których bądź nie możesz, bądź nie chcesz wykonywać.

Twoje potrzeby jako opiekuna rodzinnego są rozpoznawane i odpowiednio adresowane.

Będąc opiekunem współtworzysz nabierające znaczenia źródło wsparcia, które jest odpowiedzią na potrzeby przyrastającej w naszej populacji liczby chorych lub mniej sprawnych starszych osób. W wielu społecznościach lokalnych (czy np. gminach), publiczne i prywatne organizacje zaczynają rozpoznawać tę istotną rolę pełnioną przez opiekunów rodzinnych, chcą zorientować się, kim jesteście i służyć Wam wsparciem. Rodzaj dostępnej pomocy różni się w zależności od tego, czym dysponuje dana społeczność (gmina). Zazwyczaj ta pomoc obejmuje takie usługi, jak dostarczanie posiłków czy pomoc przy obsłudze bliskiej Ci osoby, pomoc domową czy pomoc w zakupach. Inny rodzaj wsparcia może polegać na szkoleniach czy dostarczaniu materiałów informacyjnych, spotkaniach grup wsparcia, itd. Jeżeli lokalne zasoby nie są dostępne, cenne mogą okazać się materiały wydawane na poziomie ogólnopolskim.

Kiedy szukać pomocy?

Im wcześniej uzyskasz pomoc czy wsparcie, tym lepiej będziesz w stanie radzić sobie w długotrwałym procesie opieki i utrzymywać dobre samopoczucie. Nie czekaj, aż pojawi się sytuacja kryzysowa. Jeżeli jesteś opiekunem rodzinnym, od razu uczyń krok w kierunku poszukiwania wsparcia.

W jaki sposób zacząć otrzymywać pomoc której potrzebujesz?

Rozpocznij, poprzez kontakt z jedną z lokalnych organizacji wymienionych w tej broszurce. Na przykład skontaktuj się z lokalnym Biurem ds. Osób Starych i zapytaj, czy jest tam ktoś, kto może ci pomóc rozpoznać Twoje potrzeby. Możesz też zamówić jedną z wymienionych broszur. Za każdym razem, gdy dotrzesz do jednego ze źródeł, dowiesz się o kolejnych, które spowodują, że poczujesz się mniej przytłoczony przez liczne i ważne zadania w pełnieniu roli opiekuna rodzinnego.

Lokalne organizacje mogą pomóc Ci w zadbaniu o samego siebie oraz członka rodziny czy przyjaciela.

Znalezienie osoby lub źródła pomocy, którego potrzebujesz, może wymagać poszukiwań np. w Internecie lub wykonania kilku rozmów telefonicznych. Skorzystasz z tych źródeł, jeżeli nie zrezygnujesz z dotarcia do odpowiedniego źródła np. zaraz po pierwszej rozmowie telefonicznej, w której nie uzyskasz interesujących cię informacji Otwierając książkę telefoniczną na tzw. „żółtych stronach” znajdziesz tam różne organizacje, z którymi możesz skontaktować się, aby uzyskać niezbędne informacje na temat źródeł wsparcia takich jak: profesjonalna medyczna opieka domowa, pomoc w sprzątaniu, pomoc w załatwianiu spraw finansowych i prawnych, zajęcia rekreacyjne. Wśród źródeł pomocy, które przydatne są w opiece, można wymienić następujące:

1. Te źródła, które odnoszą się do opieki w domu:

- Usługi opiekuńcze – są skierowane do osób starszych, chorych, niepełnosprawnych, które mają trudności, np. z robieniem zakupów, sprzątaniem, higieną osobistą, wymagają opieki rehabilitanta. Te usługi są one świadczone w mieszkaniu osoby, która potrzebuje pomocy. Wśród usług opiekuńczych wyróżniamy:
    - usługi gospodarcze: pomoc w codziennych zajęciach, takich jak robienie zakupów, sprzątanie, gotowanie, załatwianie spraw w urzędach itp.
    - usługi pielęgnacyjne: mycie, kąpanie, ubieranie, pomoc dla osób chorych, dozowanie lekarstw, prześcielanie łóżka, zapobieganie powstawaniu odleżyn i odparzeń, karmienie.
    - usługi specjalistyczne to specjalistyczne formy pielęgnacji, rehabilitacja fizyczna, terapia. Jest to szczególny rodzaj usług dostosowanych do rodzaju schorzenia lub niepełnosprawności. Są one świadczone przez specjalistów, np. pielęgniarki, rehabilitantów, psychologów, terapeutów.
- Usługi świadczone przez ośrodki pomocy społecznej (OPS) Pamiętajmy, że należy zgłaszać się do OPS w miejscu zamieszkania (dzielnicy).
- Usługi świadczone przez organizacje pozarządowe (tzw. NGO), typu Caritas Polska, Polski Czerwony Krzyż czy Polski Komitet Pomocy Społecznej.
- Dzienne ośrodki pobytu – to miejsca całodziennej opieki, w którym osoby starsze m.in.: wspólnie spędzają czas, mają zapewnione wyżywienie, rozwijają zainteresowania, organizują koncerty, prelekcje, uczestniczą w wycieczkach do muzeów, teatrów, często mają zapewniony dostęp do różnych usług, np. pralni, fryzjera etc. W ośrodkach tych może też być prowadzona działalność rehabilitacyjna.

2. Rodzinne domy pomocy społecznej (RDPS) dla osób w podeszłym wieku

Jest to nowa forma usług świadczonych w ramach pomocy społecznej. Zadaniem rodzinnych domów jest zapewnienie całodobowej opieki dla nie mniej niż 3, a nie więcej niż 8, osób w podeszłym wieku, wymagających z powodu wieku wsparcia w tej formie.

Osobom wymagającym, z powodu wieku, wsparcia RDPS świadczy przez całą dobę:

- usługi opiekuńcze zapewniające: udzielanie pomocy w podstawowych czynnościach życiowych, w tym pielęgnację w czasie choroby oraz pomoc w korzystaniu ze świadczeń zdrowotnych, opiekę higieniczną, w miarę potrzeby pomoc w ubieraniu się, jedzeniu, myciu i kąpaniu, organizację czasu wolnego, pomoc w zakupie odzieży i obuwia, niezbędną pomoc w załatwianiu spraw osobistych, kontakty z otoczeniem,
- usługi bytowe zapewniające: miejsce pobytu, wyżywienie, utrzymanie czystości.

3. Domy pomocy społecznej (DPS)

- zapewniają całodobową opiekę oraz zaspokajają niezbędne potrzeby bytowe, edukacyjne, społeczne i religijne na poziomie obowiązującego standardu;
- są miejscem pobytu dla osób starszych, które wymagają opieki i pomocy (np. ze względu na stan zdrowia) i jednocześnie nie ma możliwości zapewnienia im tej pomocy w miejscu zamieszkania;
- dają schronienie (tzn. po prostu się w nim mieszka), wyżywienie; w domu otrzymuje się też odzież i środki czystości. Senior ma zapewnioną opiekę pielęgniarską, pomoc w

robieniu drobnych zakupów, np. kupno codziennej gazety czy ulubionych owoców (jeśli nie wychodzi na zewnątrz);

- domy powinien też dbać o rozwój i dobre samopoczucie swoich podopiecznych: pomagać im w samousprawnianiu (przez ćwiczenia, terapię zajęciową), rozwoju zainteresowań i ciekawym spędzaniu wolnego czasu, ułatwiać kontakty z rodziną.

4. Zakłady pielęgnacyjno-opiekuńcze prowadzą opiekę całodobową, obejmującą świadczenia o charakterze pielęgnacyjnym, opiekuńczym i rehabilitacyjnym, leczenie farmakologiczne i dietetyczne dla pacjentów niewymagających leczenia szpitalnego. W zakładach tych pacjent może przebywać na czas określony.

5. Zakłady opiekuńczo-lecznicze udzielają całodobowych świadczeń zdrowotnych, które obejmują swoim zakresem szeroko rozumianą opiekę i leczenie osób, które przebyły ostrą fazę leczenia szpitalnego i mają ukończony proces diagnozy, leczenia operacyjnego lub intensywnego leczenia zachowawczego. W zakładach tych pacjent może przebywać na czas określony lub na stałe.

6. Hospicja (stacjonarne, dzienne, domowe), które służą opiece nad osobami ciężko chorymi, dla których nie ma nadziei na wyleczenie. Hospicja, oprócz pomocy w opiece, prowadzą też często poradnictwo lekarskie oraz „uczą" domowej opieki, podstawowych zabiegów pielęgnacyjnych. Ciekawą inicjatywą są tzw. hospicja domowe, organizowane społecznie przez fundacje, stowarzyszenia, grupy charytatywne, które świadczą usługi medyczno--opiekuńcze w domu na rzecz osób nieuleczalnie chorych, np. w terminalnej fazie choroby nowotworowej.

Opracował Piotr Czekanowski na podstawie:

1. “A Path For Caregivers” written by Karalee T. German. American Association of Retired Persons (AARP). A Publication of the Program Coordination and Development Department.

2. Wyników z polskiej części badań wykonanych w ramach projektu EUROFAMCARE zatytułowanego „Usługi wspierające opiekunów rodzinnych osób starych w Europie: charakterystyka, zasięg i korzystanie”, zrealizowanego w latach 2003-2005. Projekt ten (QLRT-2001-02647) współfinansowany był z funduszy Unii Europejskiej. Więcej informacji na temat całego projektu można znaleźć na stronie internetowej: www.uke.uni-hamburg.de / eurofamcare.

3. „Vademecum seniora. Przewodnik po uprawnieniach”, 2002, Stowarzyszenie Klon / Jawor, Warszawa.

Broszura dla usługodawców (makieta)

Jesteś jednym z najważniejszych ogniw systemu opieki nad starszym, niepełnosprawnym człowiekiem. Oczywiście, znasz doskonale swoje obowiązki i zadania, wiesz dobrze, jak pomóc takiej osobie i czego ona rzeczywiście potrzebuje. Wiesz także, że nie wszystkie z jej oczekiwań można spełnić. Cóż, ograniczone możliwości i potencjał kadrowy twojej placówki, czy potrzeby starszego człowieka daleko wykraczające poza zakres działania Twojej instytucji lub organizacji uniemożliwiają często zaspokojenie jego oczekiwań. Poza tym – przecież on / ona – Twój podopieczny – ma rodzinę i to ona powinna dołożyć starań, by ułatwić życie starszej osobie...

Z drugiej strony – gdyby choć trochę jej pomóc, może poprawa jej samopoczucia okazałaby się znacznie większa, niż wysiłek włożony w zaspokojenie jej potrzeb? Tylko jak tego dokonać przy ciągle ograniczonych możliwościach i niedostatkach, którym musisz stawić czoła?

* * *

Proponujemy Ci kilka wskazówek, jakie formułujemy na podstawie naszych doświadczeń wyniesionych z kilkuletniej realizacji programu badawczego EUROFAMCARE[*]. Przeznaczona dla Ciebie i pracowników Twojej placówki broszura jest jedna z dwóch opracowanych przez nas. Druga została zaadresowana do starszych niepełnosprawnych osób. Łączy je jednak wspólny mianownik, którym jest hasło:

NIE JESTEŚ SAM!

Nie jesteś sam, gdy masz ocenić, jakiej pomocy Twój podopieczny potrzebuje najbardziej

Nie jesteś sam, gdy planujesz program opieki nad podopiecznym.

Nie jesteś sam, kiedy przystępujesz do realizacji tego programu.

Nie jesteś sam, kiedy w trakcie opieki nad starsza osoba pojawiają się nowe problemy.

Nie jesteś sam, kiedy z podopiecznym trzeba rozmawiać o bardzo poważnych sprawach.

Nie jesteś sam. Masz sprzymierzeńców i partnerów. Ta świadomość powinna Ci towarzyszyć i być pomocna w codziennej pracy. Więcej instytucji i organizacji zajmujących się opieka nad osoba starszą to **szansa dla współpracy, a nie współzawodnictwa.**

Kto udziela pomocy starszym ludziom?

Lista usługodawców nie w każdej gminie jest bardzo długa, zawsze jednak znajdują się na niej przynajmniej dwie pozycje:

- Poradnia lekarza rodzinnego
- Gminny Ośrodek Pomocy Społecznej

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[*] Badanie w ramach projektu EUROFAMCARE zatytułowanego „Usługi wspierające opiekunów rodzinnych osób starych w Europie: charakterystyka, zasięg i korzystanie" zrealizowane zostało w latach 2003 – 2005. Projekt o symbolu QLRT-2001-02647był współfinansowany z funduszy Unii Europejskiej. Więcej informacji na temat całego projektu można znaleźć na stronie internetowej: www.uke.uni-hamburg.de/eurofamcare/.

Obie placówki mają do spełnienia ważną rolę w stosunku do starszych osób niepełnosprawnych, a mianowicie dostarczenie im podstawowych świadczeń w zakresie ochrony zdrowia i pomocy materialnej (o ile jest niezbędna) lub świadczeń opiekuńczych. Niezależnie od tego, jak kształtowały się w przeszłości relacje między służbą zdrowia a pomocą społeczną, obie instytucje „skazane” są na współpracę.

Dlaczego powinieneś szukać partnerów?

Odpowiedź jest oczywista: z racji określonego zakresu kompetencji i zadań Twojej placówki nie jest ona w stanie rozwiązać wszystkich problemów osoby starszej. Ty też raczej nie znasz się na wszystkim. To nie przyniesie uszczerbku renomie Twojej placówki, jeśli zwrócisz się o pomoc lub konsultację do pracowników innej. Dotyczy to szczególnie tych sytuacji, kiedy pracownicy pomocy społecznej szukają pomocy u pracowników służby zdrowia, a ci drudzy – w sektorze pomocy społecznej. Wykorzystanie kwalifikacji pracowników obu pionów zajmujących się opieka nad osobą starszą przynosi efekty synergiczne – mimo mniejszego nakładu pracy uzyskujemy lepsze rezultaty. **Wykorzystanie kilku usługodawców z różnych obszarów opieki nad osoba starszą sprzyja poprawie jakości jej życia**. Gdzie zatem szukać partnerów?

Instytucje samorządu terytorialnego

Ich zadaniem nie jest bezpośredni udział w sprawowaniu opieki, ale w organach samorządu znajdziesz informacje o adresach i zakresach kompetencji ważnych dla Ciebie instytucji, Należą do nich m.in. Sąd Opiekuńczy i Rodzinny oraz placówki poradnictwa prawnego i socjalnego. **Jeśli nie znasz adresów wszystkich instytucji, z których pomocy możesz korzystać, to nic w tym złego. Powinieneś jednak wiedzieć, gdzie tych informacji szukać.**

Placówki udzielające pomocy w ramach służby zdrowia

Jeżeli działasz w takiej miejscowości, w której funkcjonują inne podmioty działające w obszarze opieki medycznej nad osobą starszą, to zapewne w Twojej miejscowości lub na terenie Twojego powiatu znajdziesz wśród nich:

- przychodnie specjalistyczne
- oddziały geriatryczne w szpitalach
- zakłady pielęgnacyjno-opiekuńcze
- zakłady opiekuńczo-lecznicze
- hospicja
- pielęgniarka środowiskowa
- agencje pielęgniarskie

Każda z tych placówek świadczy usługi z zakresu ochrony zdrowia, począwszy od konsultacji lekarzy specjalistów przez zapewnienie systematycznej opieki pielęgniarskiej aż po opiekę z stanach terminalnych. Zależnie od potrzeb możesz poszukiwać pomocy odpowiedniej placówki, pamiętając, że w przypadku placówek zamkniętej służby zdrowia niezbędne jest skierowanie lekarza opieki podstawowej. **Jeśli masz wrażenie, że stan zdrowia osoby starszej ulega zmianom, podziel się swoimi uwagami z lekarzem lub**

pielęgniarką. Oni wskażą Ci dalszą drogę postępowania lub sami zajmą się osoba starszą.

Zakłady pielęgnacyjno-opiekuńcze zapewniają całodobową opiekę, która obejmuje świadczenia o charakterze pielęgnacyjnym, opiekuńczym i rehabilitacyjnym, leczenie farmakologiczne i dietetyczne dla pacjentów niewymagających leczenia szpitalnego. W zakładach tych pacjent może przebywać przez okres do 6 miesięcy.

Zakłady opiekuńczo-lecznicze zapewniają całodobowe świadczenia zdrowotne, obejmujące opiekę i leczenie osób, które zakończyły leczenie szpitalne i mają ukończony proces diagnozy, leczenia operacyjnego lub intensywnego leczenia zachowawczego. W zakładach tych pacjent może przebywać na stałe.

Hospicja (stacjonarne, domowe)maja zadanie zapewnienie opieki nad osobami w stanie terminalnym. Hospicja umożliwiają często także korzystanie z poradnictwa lekarskiego oraz instruują w zakresie sprawowania domowej opieki i dokonywania podstawowych zabiegów pielęgnacyjnych. Hospicja domowe, organizowane najczęściej przez fundacje i stowarzyszenia, świadczą usługi medyczno--opiekuńcze w domu.

Usługi rehabilitacyjne

Wśród zadań związanych ze sprawowaniem opieki nad starsza osoba badaj najbardziej niedocenianym jest rehabilitacja. Tymczasem prawidłowa rehabilitacja, prowadzona w mieszkaniu starszej osoby lub we właściwej placówce nie tylko opóźnia utratę sprawności, ale ułatwia osiągnięcie poprawy zdrowia i sprawności w przypadku chorób przewlekłych lub po stanach chorobowych. Innymi słowy, dobra rehabilitacja to wyższy poziom sprawności osoby starszej, a zatem mniejszy zakres zadań placówki sprawującej opiekę. Poza placówkami rehabilitacyjnymi w ramach zakładów opieki zdrowotnej możesz znaleźć prywatne placówki, mające podpisane odpowiednie umowy z Narodowym Funduszem Zdrowia na udzielanie usług rehabilitacyjnych. Ćwiczenia rehabilitacyjne ułatwiają ponadto utrzymanie rozmaitych nawyków osoby starszej i zachowanie samodyscypliny, co ma duże znaczenie dla skuteczności podejmowanych przez Ciebie działań w stosunku do starszej osoby. **Jeśli sądzisz, że utracona sprawność osoby starszej może być choć częściowo przywrócona, skontaktuj się z pracownikiem służby zdrowia lub bezpośrednio z rehabilitantem. Oni podejmą właściwe działania.**

Placówki udzielające pomocy w ramach środowiskowej pomocy społecznej

Do świadczeń pomocy społecznej należą świadczenia materialne (w formie pieniężnej i rzeczowej) oraz usługowe. Te pierwsze mogą ułatwić pokonanie barier materialnych w organizacji opieki nad osoba starszą, zwłaszcza opłacenie niektórych świadczeń, drugie natomiast to świadczenia opiekuńcze, związane z pomocą w prowadzeniu gospodarstwa domowego lub specjalistyczne świadczenia opiekuńcze, udzielane osobom ze schorzeniami psychicznymi. **Jeśli uważasz, że jakość życia osoby starszej obniżają niezaspokojone potrzeby związane z organizacją życia w gospodarstwie domowym, zwróć się do gminnego / miejskiego ośrodka pomocy społecznej. Pracownik socjalny po przeprowadzeniu wywiadu środowiskowego zaproponuje odpowiednią pomoc.**

Jeżeli osoba starsza potrzebuje pomocy w ciągu dnia i nie musi przebywać stale w swoim mieszkaniu, niektóre funkcje opiekuńcze mogą przejąć pracownicy domu dziennego pobytu. Warto wiedzieć, że ddp udzielają świadczeń po uzyskaniu skierowania z GOPS / MOPS i ustaleniu zasad odpłatności. Jeżeli twój podopieczny dysponuje niskim dochodem, prawdopodobne jest zwolnienie go z odpłatności za te usługę.

Placówki udzielające pomocy w ramach instytucjonalnej pomocy społecznej

Domy pomocy społecznej oferują miejsca dla tych osób, które nie mogą samodzielnie pozostawać w swoim gospodarstwie domowym i są zmuszone do stałego korzystania z pomocy. Wśród typów domów pomocy społecznej wyróżniamy m.in. domy dla:

- Osób w podeszłym wieku
- Osób przewlekle somatycznie chorych
- Osób przewlekle psychicznie chorych
- Dorosłych niepełnosprawnych intelektualnie
- Osób niepełnosprawnych fizycznie

Skierowania do dps wydaje Powiatowe Centrum Pomocy Rodzinie na wniosek GOPS. W zależności od sytuacji osoby starszej **Jeżeli według Ciebie osoba starsza nie może pozostawać w swoim gospodarstwie domowym bez stałej opieki, a nie ma możliwości zapewnienia takiej opieki, zwróć się do ośrodka pomocy społecznej. Pracownik socjalny zaproponuje właściwą drogę postępowania.**

Niektóre dps oferują możliwość czasowego pobytu osoby starszej. Jest to szczególnie ważne w przypadku okresowego braku możliwości zapewnienia osobie starszej należytej opieki, np. w przypadku choroby lub wyjazdu opiekunów.

Organizacje pozarządowe

Ten partner jest ciągle jeszcze za mało doceniany, ale warto zwrócić na niego uwagę. Organizacje pozarządowe mogą stać się Twoim partnerem, któremu będzie można zlecać wykonywanie różnych zadań z zakresu opieki i pielęgnacji osoby starszej. Współpracownicy organizacji pozarządowych legitymują się coraz lepszym przygotowaniem do wykonywania swoich funkcji. Silną stroną tych organizacji jest często wola działania i kwalifikacje, do słabych należą braki w wyposażeniu i ograniczony przestrzennie zakres działania. **Jeśli jesteś zdania, że przynajmniej część Twoich zadań może przejąć organizacja pozarządowa, realizująca przy tym Twoje wskazówki i zalecenia, zaproś ją do współpracy. Przepisy pozwalają na zawieranie takich umów i rozszerzanie rynku usług społecznych.**

Wolontariusze

Poza organizacjami społecznymi możesz znaleźć w swoim otoczeniu osoby, które są gotowe do współpracy bez formalizowania jej zasad i bez przynależności do jakiejkolwiek organizacji pozarządowej. Łatwo dostrzeżesz, że osoba starsza oczekuje nie tylko fachowego i punktualnego wykonywania prac opiekuńczych i pielęgnacyjnych, ale potrzebuje towarzystwa, okazji do rozmowy i bezinteresownego zainteresowania. To mogą zapewnić wolontariusze. Postaraj się zatem skupić ich grupę wokół Twojej placówki, a dostrzeżesz, jak ich obecność przy osobie starszej korzystnie wpłynie na jej samopoczucie. **Jeśli w Twojej opinii poza profesjonalną, kwalifikowaną pomocą osobie starszej brakuje towarzystwa i pomocy w prostych czynnościach, zaproś do sprawowania opieki wolontariuszy.**

Rodzina osoby starszej

Partnerem, z którym najczęściej spotykasz się sprawując opiekę nad osoba starszą, a którego – czasami – najmniej doceniasz, jest jej rodzina. To ona, o ile jest w pobliżu, dźwiga na sobie największy ciężar opieki, wysiłek finansowy i obciążenie budżetu czasu. Opiekunowie rodzinni są tymi, którzy zazwyczaj jako pierwsi dostrzegają zmiany w stanie zdrowia i zachowaniu osoby starszej, którzy najdłużej w ciągu doby są przy osobie starszej i którzy wkładają w swoje zadania największy ładunek emocjonalny. To zarazem Twój najbliższy partner. Każde partnerstwo potrzebuje jednak zachowania relacji równości między oboma stronami oraz docenienia.

Jeśli chcesz podnieść poziom opieki nad osoba starszą bez zwiększania obciążenia Twojej placówki, doceń i dowartościuj rodzinę. Udzielaj jej pełnych i zrozumiałych dla niej informacji o stanie i potrzebach osoby starszej, upewniaj się, że jest w stanie wywiązać się z nałożonych na nią zadań i staraj się ją instruować, by możliwie najmniejszym wysiłkiem realizowała swoje zadania.

Uwagi końcowe

Sugestie, które znalazłeś w tekście niniejszej broszury, nie maja na celu podważenia twoich kompetencji i dobrej woli. Przeciwnie, jesteśmy przekonani, że ze wszystkich sił dążysz do tego, by Twoi podopieczni mieli możliwie najlepsze warunki. Zdarza się jednak, że skoncentrowani na własnych zadaniach zapominamy, że potrzeby każdego człowieka odnoszą się do różnych obszarów jego życia. Poszukiwanie partnerów w sprawowaniu opieki to zatem nie dowód słabości, ale wyraz świadomości, że dzięki dobrej współpracy specjalistów z różnych dziedzin poprawimy jakość życia osoby starszej, a to będzie powodem naszej satysfakcji. Tego Ci życzymy.

Opracował Piotr Błędowski i polski zespół badawczy w ramach projektu EUROFAMCARE

4.5 Greece

Due to the current lack of recognition of family care of dependent older people as a general issue in Greece, the Greek team decided not to produce guidelines for family carers and service providers at this stage, but to concentrate on the dissemination of the survey results and main EFC findings to these two target groups, with a view to promoting collaboration and discussion and involving them in further activities, which may include the production of guidelines. The only family carer organizations that exist in Greece are the Alzheimer Association family support groups with whom we are working closely (see REACT activities above) and work with service providers is also proceeding via the Local Authorities as described above and below.

The main thrust of the Greek team's efforts is concentrated on the promotion to policy makers and service providers of the **Recommendations and proposed actions to promote the cause of family carers in Greece.**

The EUROFAMCARE study and specifically the Greek National Survey, provides detailed data on the situation of family carers in Greece, together with comparative data from samples from 5 other EU member states. The National Report on the survey is used as a basis for the following recommendations for actions to support Greek family carers of dependent older people, which could lead to the construction of a Greek Action Plan for the support of Greek family carers, within the framework of continuing collaboration with the Local Authorities.

Issues

Virtually nowhere in Greece is family care on the political agenda. The only exception has been the start up of various associations and NGOS providing support to family carers of people with Alzheimer's disease; these have generally been very well accepted and the support they offer much appreciated, thus validating the argument that promoting the issue of family carers of older dependent people in Greece, is not only an urgent necessity but also long overdue.

Another source of possible change, though more theoretical given the current high unemployment rate, is the political commitment to increase labour market participation which will involve employing more women and also people at later stages of their life (Lisbon goals).

Thus there are a limited set of strategies for promoting the findings from the EUROFAMCARE research study in Greece.

- To work closely with existing NGOs and associations working with family carers; the aim of this would be to provide them with data and the findings from the EFC study which can be used by them in advocacy work. Examples of the kind of data that can be used are:
    - Greek carers, as compared to those in the other 5 EUROFAMCARE country samples, reported the highest relative costs associated with caring and at the same time had inadequate incomes to meet the extra costs of care. In many cases such costs should not have to be met e.g. costs in using a national health service. Financial help is needed to cover some of the extra costs arising from caring and to ensure family carers do not find themselves uninsured, and with inadequate pension coverage later in their life.
    - Under-use of existing services, reported by both family carers and service providers, suggests some of the current inadequacies in the limited services available; the data show that FCs will not use services for older people that provide care inferior to that which they themselves provide, indicating the need for better quality services. FC associations need to promote a more person centred approach, outreach services, integrated care, responsive services, and the recognition that coverage, especially for those who are working, may need to be all year round and over 24 hours.
    - The lack of services for both dependent older people and their family carers, compared to other countries, suggest the need for some form of advocacy to promote their interests and common issues. FC associations need to push for new services and forms of support e.g. genuine respite care for family carers both for programmed holidays and emergencies, support for working carers, support especially though not exclusively targeted on those with behavioural problems.
    - Data on family carers in other EFC countries (UK and Sweden) indicate that whilst also providing similar levels of care, they have better psychological well-being and quality of life than Greek carers, and at the same time are supported by an extensive network of practical care and financial support services. This leads to the recommen-

  dation that the needs of family carers should be recognized and included in integrated health and social care services for older people,

  - The new NGO for people over 50, 50+ Hellas, will be promoting the findings from the EFC programme. However, the NGO will have as one of its main tasks the implementation of some of the main findings from the Greek National Survey; in particular the most important need expressed by family carers was for **Information**
    – on the different types of services available and on the rights to support and services for both older people and family carers,
    – about the disease of the older person and other conditions common in old age e.g. deafness, memory problems etc.;
    – about health promotion, disease prevention, early diagnosis and treatment, in order to maintain the older person's independence and autonomy as far as possible;
    – on how to protect their own physical health whilst providing care for a dependent person e.g. care techniques, lifting, bathing, incontinence care etc., and how to protect and maintain their own good psychological health and well-being.

- Work with the public sector. Very low political priority has been given to supporting families through adequate and comprehensive welfare measures. In order to convince politicians at national level of the imperative need for such family carer support, two strategies are being developed to influence policy and practice.

  - Work at the EU and the national levels, which will ensure that governments will have to report on and consider the support of family carers. The Greek team remains active in promoting the issue of FC support at the EU level since only with pressure from the EU will Greek politicians feel they have to consider what actions to take. We have also managed to include some elements of support for FCs on the Ministry of Health and Social Solidarity's 5 year Strategic Plan 2007-13. An important move could be to promote the adoption of national standardized evaluation and monitoring procedures for all services and use these as a basis for future funding.

  - Work at the level of Local Authorities to promote discussion about how best to support the FCs in their areas. Discussions are underway with IKPA (a newly formed "think tank" called the Institute for Social Welfare and Solidarity) to undertake some common actions to present work concerning supporting families in public policy to representatives from the LAs.

  - Training of local services and care workers to recognize FCs and offer support in accordance with their needs.

Suggested Areas for Support of family carers

- Emotional-psychological support e.g. trained volunteers, as a way providing some respite care.

- Mobility aids and technical adaptations in the home.

- Improved mobility outside the house through environmental modifications and the adoption of new building standards in all built environments to take into account the needs of the physically impaired; a particular need in Athens is for accessible and safe pavements!

- Legal protection for older people, especially those living alone, against financial mismanagement and theft of the OP's property.
- Well organized, year round support for those caring for the most dependent OP.
- Training for both FCs and professionals in services for older people is vital to the provision of good quality care.

Labour Issues

- A major issue that has to be addressed at local, national and EU levels is how to recruit and develop an adequate care workforce. Though a training course has been run for migrant care workers under the EQUAL programme, this was a one-off programme and there is a need for such training to be offered systematically and with certification.
- Further suggestions include the development of skills in comprehensive needs assessment which can be used by services (primarily) and the social insurance funds for correct resource (disability benefits and pensions) and service allocation. Occupational / ergo-therapists are a professional group in Greece which has developed new skills and areas of expertise which could be particularly appropriate to such assessment work and training, and discussions will be held with them.

4.6 The United Kingdom

The UK has probably the most comprehensive legislative framework on carers in the world, with there being several governmental acts that in principle provide carers with certain statutory rights. The varying systems of devolved government now in operation in the UK mean that legal and statutory rights vary slightly from country to country. However, despite this, initiatives to promote better services for carers have been variously developed over the last decade or so. Moreover, there are several well established carers' organisations operating in all the four home countries. The picture is further complicated by the fact that most local authorities have developed their own systems of assessment. In view of the above factors, and following consultation at the REACT events, it was considered inappropriate to produce a generic set of guidelines and manuals for practice. Rather, the preferred method of dissemination was to generate a brief summary of the main findings to emerge from the NASURE, with a particular emphasis on assessment and issues of quality, and to distribute this widely to stimulate further debate and to highlight areas in need of attention. This document is currently being produced and will be made available to the REACT participants and other key stakeholders for comment and modification.