



## **Increasing Employability and Standards of Elderly Caregivers through Specialized Training and Innovative Empowerment**

**O7. Elaboration of a model of intervention to support elderly caregivers in order to reduce public costs.**



**Erasmus+**

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## 1. Introduction and definition of the social context.

The last general-population surveys that have been developed in several countries reveal us an ongoing life expectancy's increase, in particular in countries where the economic development has encouraged the basic needs' satisfaction, nutrition and health care mainly.

In some of these countries, the reduction of birth rate remains as status and, in the future it will define an elder population. The extension of people's average age, will cause an increase of time for the elder's health care needs.

The common meaningful question now is "which role" should have today and will have in the future the single countries' welfare social politics.

In this scenario, caregiver takes an increasingly meaning role in the health care governance, both for the public expenditure decreasing and within the family and social community's structure (informal carer or voluntary).

We observe a continuous unrest that see as actors state administration and family involved to define the responsibility that them must or should assume in relation to non self-sufficient elder citizens' health care and assistance. To which extent should the state administration ensure specific services and health assistance to non self-sufficient elder citizens?

Meanwhile every study about informal cares intervention, new types of association whose members are involved with a heavy care burden, the development of social welfare politics, that are identified with through the de-institutionalisation and community care; have contributed to open new paths so the social services could seriously work with carer, or better "helping the helpers". It should be noted that in the past the carer's role it's been neglected, now the interest for this kind of figure is getting stronger. Several studies have highlighted the fact that assistance givers are never a homogeneous group, actually the carer's role involve a range of persons about whom it's possible to define some generalisation but we can't forget or underestimate basic differences.

For example, there's a need to highlight the family relationships; some 4 carers out of 5 belong to the parental network (Green, 1988; in "Aiutare i carer" ed. Erickson 2002), usually the measure of the sense of responsibility depends on the degree of relationship, closer is the relationship, more is the commitment about person's care.

So it's better to note the difference between carer's parental roles, actually between married, son/daughters, brother/sister, nephews.

Another element of difference to take in account is the carer's gender; women take care of the single person's assistance, men prefer to afford procedures and bureaucracy. These roles are influenced by social, cultural and psychological factors.

Cohabitation between carer and relatives is another factor that can define a difference related to the different physical and psychological involvement.

The carer's age is index too of meaningful differences, in particular when he's too old or too young. Today there's a necessity to consider the carer's ethnic minority. He could be maybe in a more unfavourable condition than citizens members of the nation peculiar ethnic group, at least in relation to the possibility to access to assistance services.

The single carer's care burden is heavier than the carer that can share it with sisters, brothers, sons, daughters.

In different western countries, talking about a possible future welfare, it's been acted an experimentation; a different way to approach to the elder persons that need cares, they are getting the general purpose, actually social acts are not addressed to single persons but to the whole community that is the potential and decisive resource against single person's existential distress. In the European Union, this intervention model is widely used. The training courses that are proposed to social assistants and social workers are focused on the community carer interventions, group works and network development. Citizens shall be more and more involved as actors within the health care practice and within the definition and organization of services that are targeted at an individual.

To understand how a social service can act properly, in support to caregivers it is not only a question of pure civilization aiming at assure to citizens better condition of welfare, but it represents a tool of sound management of public finance.

It is within this ongoing cultural, social and professional tension that are developing different model of intervention supporting to caregivers. These models are all based mainly on principles of general application that must be adjusted according to the different policies and organization of social services existing at national, regional and local level in the different European Member States.

In this document, after a short presentation of 10 guide principles of general application, we will make a confrontation of the different policies and organization of social services in Italy, Turkey, Romania and Portugal.

At last we will present a case study, the project "By your side" developed by the Municipality of Florence and active since 2011.

## **2. Values and Principle Underpinning for the Caregiver model of intervention.**

The group of study of IESEC project's has identified the following 10 principles of general application for the design of a model of intervention at local level. These principles are mainly based of a community approach and they respect the different work methodologies, welfare and social politics existing in the European Member States.

### **1. Caregiver Inclusion and Voice**

- ✓ No one person is given more value or respect than another.
- ✓ Caregivers should be recognized and valued, while realizing that no two caregivers are alike.

- ✓ Caregivers should be engaged in the process of developing, implementing, and evaluating the programmes.

## **2. Collaboration**

- ✓ For caregivers, the needs for support regarding non-medical activities of daily living are as important as a biomedical focus.
- ✓ Support for caregivers is everyone business- not only in the domain of health services.
- ✓ Inter- agency communication, networking and capacity building is the only viable way to develop caregiver programmes .
- ✓ Good communication is a cornerstone in developing and delivering programmes and services that sustain caregiving.

## **3. Evidence Informed**

- ✓ Programmes must be informed by the best available evidence found in the peer reviewed literature and the experiential knowledge of those receiving services and those delivering them. This includes caregiver assessment tools and proven caregiver interventions programmes.
- ✓ It is necessary to plan for monitoring and evaluation when you design your programme, policy or service; this will help you design and maintain an effective policy, programme or service.
- ✓ Programmes should have mechanisms in place to ensure inclusion of caregiver perspectives and experiences.

## **4. Respect and Dignity**

- ✓ Family caregivers must be acknowledged, respected and valued for their caregiving work .
- ✓ Respect is conveyed through language used to refer to caregivers and caregiving which should portray caregivers positively.

## **5. Diversity and Marginalization**

- ✓ Caregivers are a diverse group, with diverse needs, desires and abilities.
- ✓ Understanding the diversity of caregivers so that they are not marginalized means being aware of how ethnicity, cultural diversity, faith, income, mental health, and sexual orientation influence a person's experience as a caregiver.

## **6. Choice, Self-Determination and Independence**

- ✓ Willingness or capacity to take on the role of caregiver cannot be assumed.
- ✓ In order for there to be genuine choice, information must be provided about what to expect in terms of the care recipients' needs and what support can be expected from the health and service system.

## **7. Accessibility**

- ✓ Supporting caregivers requires that programmes are both accessible and responsive to the needs of diverse caregivers. How a programme or service is organized, promoted, and delivered has important effects on caregivers.

## 8. Caregiver Assessment

- ✓ Family caregivers have the right to express their needs and receive support. Caregivers have the right to have their own needs assessed, not just in relation to those of the care recipient.
- ✓ Resiliency is the capacity of a caregiver to cope with stress and adversity. In the development of caregiver support, a focus on resiliency requires that we identify the individual, family and community factors that support caregivers' resiliency and those that place it at risk.
- ✓ Service providers need to be proactive and non-judgmental in asking caregivers about their self-care, the challenges they are experiencing, and what might help.

## 9. Supporting Caregivers

- ✓ There are two main components to system sustainability: appropriate staffing and education, and appropriate focus of programmes. In short, it means the right programmes at the right time.
- ✓ Even well-developed programmes may have unintended negative impacts on the caregiver. If a programme or policy has unintended negative impacts for the caregiver, this translates to negative impacts for the care recipient as well.
- ✓ Caregivers need to feel that they can trust service providers which necessitates sufficient time and sanction to develop relationships.

## 10. Sustaining programmes

- ✓ Programmes should to be flexible enough to respond to individual and immediate needs.

## 3. Analysis of the different social models in Italy, Turkey, Romania and Portugal.

To realize how our project could be managed in the different European Member States, we've put different questions about the organization of social politics and services that are offered to non sufficient elder person in 4 Member States partner of IESEC project's. The questionnaire shouldn't have collected scientific data, but the information we've collected have allowed to outline the real situation and so defining the hypothesis of the project's realization.

Meanwhile from a legislative perspective, it emerges that within the four countries above mentioned, all the national legislation defines the basis for the person's assistance according to whom must be inspired the law (local or regional) that regulate and implement the interventions.

In Romania maybe, the legislation define its basis delegating the managing to local zones or municipalities. It's quite interesting the existence of a provincial department

for the family protection in Turkey, different from Italy where the nucleus is disassembled in relation to needs' type. The definition of a provincial department for the family protection, recalls a meaningful family's "concept", the Family as single subject that must be protected as unicum and never disassembled in relation to the single member's needs. The four countries, in relation to the social protection, offer a pension scheme and possible income supplements in relation to age and individual and family economic status.

The non self sufficient elder persons in Portugal are supported by the family, in Turkey the careful for the home caring service is really present and an economical support is guaranteed as in Portugal and Italy. The subsidies for the families in support to assistance and auxilium's expenses are different in every country. In Portugal, for example, there is the possibility to obtain subsidies for glasses, hearing aids, dental prosthesis. In Romania, there's an economic support only for the service's provision (voucher), not for the care giver.

In the whole 4 countries, the state administration guarantees the assistance's regard expenses for the citizens with no-income.

In Italy there's a difference between social and health care services' costs. The costs for the public services are guaranteed by citizens taxes, according to different single income. The health assistance costs is guaranteed regardless of the income (in relation to services, not care or diagnosis. In Italy services' providing and subsidies for elder persons depends on self sufficiency level, as this define the quantity of social and health care support.

This find of difference between services for non self sufficient elder persons and services for sufficient ones doesn't exist in Portugal as there isn't the multidisciplinary Commission that could determine a difference between them. In Italy actually there's a multidimensional and multidisciplinary Commission that defines which service can be provided in relation only to the non self sufficiency.

In Turkey the multidisciplinary Commission (nurse, social assistant, doctor, physiotherapist, nutritionist, psychologist) engages itself to provide the home care's services. In both countries there's the co partnership with the single person as with the family.

Volunteer's associations, private structures or cooperatives work in agreement with the administration. In Portugal the private service is related with the health care and assistance's residencies. In Turkey there's the possibility of subsidies for the families that need residential health structures. In Italy the co-partnership in expenses is guaranteed only for structures that are in agreement with ASL (local health assistance Agency) or the municipality. Citizens can access to private structure but with no contribution from the public administration.

Based on the above it is possible to draw some conclusions:

In both the four countries, provided assistance's services are approximately similar: assisted living facility, day care centres, home care. In Romania there are Group homes/apartments for elders people, an interesting way of residency, in Italy there are studies about solidarity based coexistences for totally or partially self sufficient elder persons.

In Romania is clearly identifiable a social politic about the social exclusion phenomenon, in particular interventions to afford indigence as the interactions and

meetings between generations developed within day care centres that are opened to all ages persons.

The questionnaire identifies clearly the psychological support that Turkey administration provides for caregivers' groups. In Italy the support group provides a larger support aim, because it's managed by a social assistant and a nurse. Their role is more similar at a "facilitator" one than a specific psychological support, even if it emerges that is possible an improvement in that field.

It's possible to suggest, according to this short summary that the models of intervention could be applied in different structures, cultures, societies. It's not compulsory that the group have to be supported by a social assistant, but he must be a professional presence in direct contact with caregivers.

We must emphasize that the project can be applied in different situations at several levels (professional figures, caregivers' group, family and family assistant). The project, besides the caregivers' support group, is more adaptable to different social environments, the action is addressed to the local community through information and training practices about elder's degenerative illness, health cares and direct assistance, and about the new outsider figure, such as a nurse or a formal caregiver.

#### **4. A case study. The "By your side" project of the Municipality of Florence.**

The idea of a project for family and relatives who act as caregivers toward a dependent family care receiver has been developed over time, as a consequence of the needs showed by family caregivers users of local healthcare services. In particular family care givers ask for help in dealing with daily assistance and emotional and physical burnout originated by their continuous care dedication.

We perceive that single performances and services towards a elderly dependent person, whilst useful, are not always sufficient to relieve such burden and don't give enough support to family care givers who go through stress and psychological pressure.

A first important help came from the Italian regulation. The 328/2000 national law (artice 1) states: "...the integrated system of intervention and social services, ..., has the purpose to promote social support, giving value to initiatives of persons, to families, to self-help and reciprocity to organised solidarity".

This project, being considered model of intervention, would like to get over experimentation of work and allow its propagation. At the same time it represents a new professional methodology put into practices by social workers to address the needs in the area while integrating with health services.

The "by your side" project started in 2011 with the goal to share daily aspects of taking care elderly care receiver and to obtain support from social and health public services without costs for the public social bodies.

For such services the project is important in order to:

- ✓ value strategies and potential and actual resources existing in the group;

- ✓ provide a proximity service in long-care situations, supporting and orientating family caregivers by increasing knowledge and information on the issues related to disabling diseases;
- ✓ promote relations and forms of socialisation with the aim to strengthen the community's social network.

The model of intervention is based on two different levels, the first is carried out through support groups, and it is composed by family cares who ask to public services a support in the care of their non self-sufficient familiar elderly, or citizen who ask to participate as familiar cares. Each group is managed by two operators, a social worker and a nurse, expert in the care of non sufficient care receivers.

These support groups allow to the carer to gain multiple benefits: particularly the support group develops greater sustainability in the commitment to care, despite the care intensity that often lasts for years.

Specifically, the group of carers has favored a "strengthening of the self-esteem," has promoted the development of adaptive capacity and coping, helped them to contain the level of stress by stimulating the awareness processes, enhanced strategies and potential resources of each of them, has promoted relations and forms of socialization and increased the membership of the community social network.

The second level of intervention is represented by 3 two-month seminars performed in different places of the city of Florence.

The seminars involve not only family care givers but also all the professionals involved in the care of non sufficient elderly people such as voluntaries, doctors, nurses, social workers, house care assistants etc..

Such information-training days are a meeting and discussion place, offering a service of proximity in long-care situations, supporting the family through the enhancement of skills and information on issues related to disabling diseases.

The speakers are public servants, so their involvement is free of charge and make available to citizens and other professionals their skills, creating a synergy between the various fields of knowledge.

The topics covered include knowledge of pathologies on dementia from a clinical point of view but also from a psychological point of view, relational and communicative. Understand the new condition and needs of the care receiver, it facilitates the carer in testing tools and strategies that can give greater confidence in the performance of their role.

The professionals working in the field (nurses, social workers, physical therapists, home care workers) provide information on access to services, the practical basics of how to run the home care (i.e. the posture maneuvers from bed to chair) that avoid to the care receiver but also to carers, accidents caused by wrong movements.

Other issues related to the rights and duties of the carer hired by the family, as the contract of employment and the importance of interpersonal relationship that is established between two different cultures, are performed during the seminars.

Both parties (family and caregivers) are directly involved and a special attention is given to the mutual knowledge of their cultural origins to facilitate the understanding

of the needs of both (client, family, caregiver). During these seminars family care and home care assistants tell about their experiences and feelings.

These informations are very valuable for the public services in order to help to improve the services with innovative solutions closest to the needs of the carers.

Both the 2 levels of intervention showed above are an integral part of the public service, there is no additional expense for the public authority because each professional makes only a change to the own method of work, with the support group and information and training to the community.

The intervention model must be constantly compared to the emerging needs of the local community. This means to create a flexible model able to change in accordance with the new emerging needs of the beneficiaries (assisted and carer).

In order to give information about the problems emerged during the start up and evolution of "by your side" project we have split the implementation of such project in 2 different phases:

1. experimental phase;
2. implementation phase.

### **1. Years 2011 – 2012. Experimental phase.**

The project started in 2011 with a first experimental phase in only one city district of Florence (the n.2 city district). The first step was to identify the typology of carer. This category was identified as family members taking care their elderly familiars with the support of social services of the Municipality of Florence.

Usually Municipality of Florence provides home care services integrated with the Tuscany Region's public health care system and with the participation of voluntary associations.

Thus the cooperation with formal volunteering for the co-conduction of the group was immediately activated involving also other citizens residents in the n.2 city district.

The project was coordinated by the social services of the Municipality of Florence and the interdisciplinary team was made by social workers and nurses of the Municipality of Florence and of the ASL (local health assistance Agency) of Florence.

Participants were identified by social workers through interview, questionnaire and CBI methodology.

The individual interviews with social worker, were important in order to define the recurring topics brought by the caregivers.

Each group were made by 2 mediators, a social worker and a nurse, and 12 – 14 participants.

The duration was stated of 9 month, from October to June, and the frequency was defined in one meeting of 90 minutes, every 2 weeks. The venues were identified in libraries located in the district and the meetings were made in the afternoon.

The participants to the support group laid down the agenda. Main topics of discussion were about daily difficulties related to the role of caregiver, the management of the

relation with the care receiver and the need to understand the emotional and behavioral results connected to cognitive decay of their elderly care receiver.

Periodic confrontations with external specialist such as psychologists, physiotherapists and geriatricians were very important to define the social and medical profile of each care receiver and its own care context.

This first phase was useful to emerge some elements that affect the attendance to the support group. Particularly from the point of view of caregivers we found a culture centred on the individual, a scarce trust on the group support, and a high degree of alienation from social life due to the long period of assistance. Obviously such considerations are different depending on personal factors such as age, the family context, personal history, values, etc.

Social workers and professionals of the social and health system perceived that the group wasn't an effective «resource» for the caregiver and they asked to themselves how to develop interest and culture for the group support?

The answer was to draw a series of interventions on the community, to revise the professional methodology (social workers, medics, nurses) the realisation, follow up, and monitoring of the support group.

This revision of the group criteria of work brought in 2012 to the organization of the first edition of the seminars based on three information days for the city community on the continuous care topic, and strategies of intervention with the patients with Dementia or Alzheimer's disease.

The agenda of the first sets was the following:

#### Day 1

“Learning in order to understand: The changes that dementia brings into the person and the family members”

“Communication: not being able to understand others and them not being able to understand”

“Tools and techniques to improve communication”

«The relation with the elderly person with dementia : pet-therapy»

#### Day 2

“The caregiver family member, a resource to value and support”

“Practical suggestions for the assistance towards the person”

“Kinesological method, useful for the capability to act of the non self-sufficient person”

Practical examples

#### Day 3



“What are the difficulties when the family decides to hire a caregiver?”

“Two stories (elderly-caregiver) and two kinds of need encounter...how to make the encounter easy?”

“General information on hiring a family care”

Their stories: story sharing

During the experimental phase were developed also some evaluation tools on the efficacy of the group support on the caregiver participant.

These tools are based on the CBI (CAREGIVER BURDEN INVENTORY)<sup>1</sup>.

CBI is a multiple choice questionnaire made of 24 items, divided in 5 dimensions of burden, through which it is possible to calculate the individual score of the person, besides the total score of burden.

This scale offers a multidimensional vision of the care giving experience, since it inspects 5 different kinds of burden.

- 1) Time-dependence Burden
- 2) Developmental Burden
- 3) Physical Burden
- 4) Social Burden
- 5) Emotional Burden

The CBI is done before entering the group in order to bring out the caregiver's overall stress degree.

The questionnaire is self-administered by the caregiver, therefore the answers are related to the perception that the person has of their own condition.

The form is divided in 5 topic areas, each made of 4/5 questions, to each of which is connected an evaluation degree, from 0 to 4:

0=not at all

1=a little

2=moderately

3=quite a lot

4=very much

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<sup>1</sup> (CAREGIVER BURDEN INVENTORY) by Novak M. and Guest C., Gerontologist. 29, 798-803, 1989.

The CBI questionnaire was given to a first group of 12 caregiver at the start of the program. The results were that for the first three dimensions the score value of the forms was very high. The highest value prevails «4=very much» In 4 and 5 dimensions, the score oscillates between «0=not at all» and just a few «3=quite a lot».

After 9 months was made a first assessment of results obtained with the participation of caregivers to the groups. The assessment was made on a sample of 12 participants. Some of them participate to the group since the beginning, other since a few months. We observed significant differences.

In the 2nd dimension «Developmental Burden» and in the 3rd dimension «Physical Burden» was evident a significant decrease of the items value scale.

## **2. Years 2013 - 2014. Implementation phase.**

The second phase of the program (2013 – 2014) had the objective to spread the project to the other 4 city districts of Florence.

First of all was made a workshop of 3 meeting with the aim to educate 4 new group mediators. Target of the workshop were social workers and nurses. The workshop allowed the implementation of the project in other 4 city districts of Florence for a total of 46 caregiver participants. The monitoring was made with periodical verification of the activities developed in each group. The information and awareness campaign was made engaging social services officers and health centers.

During these phase emerged some as point of weakness the limited number of people involved in the groups. This weakness was deal with:

1. increasing the number of trained mediators with other training courses;
2. increasing the information and awareness campaign to other city public points of contact for the population of Florence (i.e. Alzheimer centers, senior centers etc...);
3. involving the social workers and nurses in the information and awareness about the services offered by the project.