

INFORMAL CAREGIVING
AND LEARNING OPPORTUNITIES:
AN OVERVIEW OF EU COUNTRIES

Report coordinated by Eurocarers, March 2016

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ABSTRACT

This report presents an overview of support services available for informal carers in the European Union, with a particular focus on learning opportunities. It provides a baseline for the European project 'TRAIning and Recognition of Carers sKills' (TRACK), aimed at developing a learning pathway for informal carers, likely to improve their situation on the labour market.

The report is based on research including a literature review, a survey answered by 36 organisations, as well as 30 succinct interviews. The report identifies the most pressing needs and expectations in terms of learning opportunities for informal carers. It provides a range of references of relevant initiatives at local, regional, national and international levels.

The report concludes by confirming the relevance of the objectives and method of the project, and pointing out the learning of existing initiatives and the challenges to be addressed.

EXECUTIVE SUMMARY

Carers are persons of all ages who provide care (usually unpaid) to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal employment framework. Approximately 80% of people requiring long-term care will receive their care from spouses, relatives and friends. Quality of life for carers is generally poorer than for the society as a whole, being a carer is often associated with poverty, isolation, frustration, ill health and depression, often together with significant difficulties to remain included in the labour market for carers of working age.

This report provides a baseline for the European project 'TRAIning and Recognition of Carers sKills' (TRACK), aimed at developing a learning pathway for informal carers, likely to improve their situation on the labour market. The project is aimed at helping to increase the relevance of Vocational Educational Training provision and to reduce shortages in the field of care, through the development of a training programme addressing informal caregivers. The project will focus in particular on the following competencies: enhancement of independent living and active aging, specific illness management (e.g. symptoms management) and transversal care competences (such as communication skills, care planning).

The report is based on research undertaken between December 2015 and March 2016, including a review of literature, a survey among Eurocarers' network and partners answered by 36 organisations active in the fields of support to carers, research and education touching on the care issue. This material gives an overview of support available for informal carers, especially training resources, and to pinpoint relevant publications and concrete initiatives. However, given the limited time and resources available, a detailed and exhaustive review of existing policies and initiatives is beyond the scope of this report. This is particularly the case since there is a lack of comparative research available in this area.

First, the report gives an overview of support services for carers in the European Union. It underlines the fact that the provision of support services varies a great deal across countries, regions and even municipalities. It can be argued that overall, carer support services clearly remain insufficient. Civil society organisations play a major role in the provision of available support services, together with public authorities and the private sector.

A second part of the report focuses on available training opportunities for carers, revealing a still insufficient, extremely fragmented and uneven development of initiatives, which are largely undocumented. Based on the research, the content of the most commonly available types of training offered, together with the current gaps in training offered are presented in detail. The importance of the obstacles encountered by carers to access training is also highlighted. Even in countries where a diversity of training opportunities is offered, the low take-up of these possibilities is a major concern.

The report identifies four types of training available:

- Professional vocational training, also open to informal carers willing to obtain a formal qualification;
- Training developed within the health sector with the aim to equip the carers with the necessary skills to maintain the health status of a patient discharged home, as well as to maintain his/her own health;
- Training developed by Civil Society Organisations(CSOs) in the continuation of their role as information providers, generally free and open to all carers in a flexible way;
- Training developed by CSOs, specifically targeted at female carers at a disadvantage on the labour market, with the view to improve their situation, characterized by an intense support and the attempt to provide certification.

Building on the analysis of existing programmes, the report identifies 'what works' when it comes to the delivery of training (use of ICT, best timing, certification).

The final part of the report presents a range of initiatives at local level, as well as finalised and ongoing relevant projects at European level, so as to allow the project partners to build on available experience. The conclusion presents the learnings applicable to the project TRACK, notably concerning the condition for an extended use of online learning, and the need to build support and training on a solid cooperation between stakeholders and a participative approach. A series of challenges remaining to be addressed in the course of the project are also listed, including tensions underpinning the definition of the carer's role at the core of the training, the funding and rolling-out of the training pathway.

The annexes include country fiches focusing in more detail in the three pilot countries (France, Germany and Spain) as well as a bibliography and a detailed presentation of the methodology and a list of people consulted.

GLOSSARY

CARERS

Carers are persons of all ages who provide care (usually unpaid) to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal employment framework.

VET : Vocational Education and Training

ECVET: European Credit System for Vocational Education and Training see: <http://www.ecvet-team.eu/en>

E-literacy relates to the skill set required to make efficient use of all of the materials, tools, and resources that are available online.

PSYCHOEDUCATION refers to the education offered to individuals with a special mental health condition and their families to help empower them and deal with their condition in an optimal way.

INTRODUCTION

Background

Carers are persons of all ages who provide care (usually unpaid) to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal employment framework. Approximately 80% of people requiring long-term care will receive care from their spouses, relatives and friends. Even in countries with a well-developed supply of formal long-term care, the number of informal carers is estimated to be at least twice as large as the formal care workforce. (Ferrer, 2015)

Obviously carers are **an inherent as well as an indispensable part of the provision, organisation and sustainability of health and social care systems**. They will become even more important in view of the changing health and care needs, due to the ageing of society and the increasing prevalence of frailty and dementia and chronic disease.

Quality of life for carers is generally poorer than for the society as a whole, being a carer is often associated with poverty, isolation, frustration, ill health and depression, together with significant difficulties to remain included in the labour market for those carers of working age. Consequently, carers' contribution will **only be sustainable if they are provided with relevant and accessible support, including learning opportunities and training**. This is also crucial in order to support carers towards high quality care, respectful of **Human Rights provisions**¹ -, to avoid cases of maltreatment and to support **deinstitutionalisation policies**.

The World Health Organisation stresses the importance of supporting carers, within the *Health 2020 Framework calling for people-centred health systems in Europe* (Ferrer, 2015). The European Commission (EC) has highlighted the advantages of supporting family carers, including via training, as a part of a range of strategies to face the challenges attached to long term care (European Commission, 2013) (European Commission, 2014). Based on this acknowledgment, the EC supports the European project TRACK (for TRaining and recognition of informal Carers' sKills) through the programme Erasmus +. By doing

¹ Notably the articles 16 (Freedom from exploitation, violence and abuse) and 19 (Living independently and being included in the community) of the United-Nations Convention on the Rights of Persons with Disabilities.

so, the EC also pursues the objective of facilitating the inclusion on the labour market of the most disadvantaged, through the development of an area of Skills and Qualification.

This project aims at designing and implementing a learning pathway for informal carers, likely to ensure the quality of the care delivered, to support the carers and to help them reconcile their personal life and their mission as carers, as well as facilitate their inclusion on the labour market, with a particular attention to carers facing dementia.

Methodology

The report builds on a Desk Research and a Field Research both conducted between December 2015 and March 2016.

The Desk Research aimed at identifying in the relevant databases:

- Relevant policy publications issued by the institutions of the European Union,
- Relevant past or on-going European projects,
- Relevant scientific literature.

The Field study was organised so as to gather both quantitative and qualitative information.

In the first stage, a survey was circulated among the members of the Eurocarers network including a series of closed-ended questions, in order to build on our in-house expertise to identify the needs of carers in terms of support and training, and the extent to which these needs were met. Indeed, Eurocarers brings together organisations of carers as well as researchers engaged in supporting carers across the European Union. This questionnaire was also circulated to the project partners. In total, 36 organisations answered this questionnaire, the outcomes of which are presented in a series of figures in the present report.

Although the above-mentioned survey also contained qualitative questions, additional qualitative information was collected through a series of 30 short interviews with:

- Respondents to the survey (in order to get a better understanding of their point of view as well as a more detailed description of the good practices mentioned)
- Other relevant experts and stakeholders (healthcare professionals, other European networks, and relevant researchers/experts) in order to ensure that their expertise and viewpoint was also captured.

In total, 58 people from 20 EU countries and Canada were consulted as part of the research process. The following 8 EU countries were not represented: Croatia, Cyprus, Czech

Republic, Lithuania, Latvia, Luxemburg, Malta, and Romania. The methodology is presented in more detail in annexes 2 and 3.

Scope of the report

The objective of this report is not to provide readers with an exhaustive and detailed description of the support and learning opportunities that are available to informal carers across the EU. This report builds on a literature review, existing good practices and projects, as well as on the expertise of a sample of relevant stakeholders in order to give an insight into the state of play of existing carers' training opportunities. As such, this publication aims to emphasise a series of **useful pointers for the development of a new carers' training programme as part of the TRACK project.**

I –SUPPORT SERVICES FOR CARERS IN THE EUROPEAN UNION: AN OVERVIEW

This chapter aims to describe the support available in the EU, and the extent to which the needs of carers are addressed. It builds on available comparative research and policy publications completed by the survey carried out by Eurocarers in between December and February 2016.

As a preliminary remark, it should be noted that, with regards to support services, this report only considers direct support to carers, and not indirect support (such as for example cash benefits perceived by dependent people that can be used to remunerate carers).

A lack of comparative studies

When aiming to describe the support services available to informal carers, one faces the lack of available comparable data and research in the area. Indeed, describing the support provided to informal carers means looking into the design of long term care (LTC) systems, national employment legislation, the huge variety of programmes and initiatives developed by public authorities, health, social and education systems at regional and local level, as well as the numerous initiatives developed by civil society organisations and the private sector.

An exhaustive overview of 'Informal care at the European level' was produced in 2010 as part of the EU funded research project INTERLINK (Triantafyllou, 2010), the report has nevertheless not been updated since, even though many developments have occurred in the last years. Research published in 2016 suggests that, despite the growing importance of the challenges faced by carers, still little is known about the availability of support for carers in Europe (Courtin E., 2014). Against this backdrop, the views of stakeholders, as collected by Eurocarers through a survey and interviews, offers a useful and enlightening perspective.

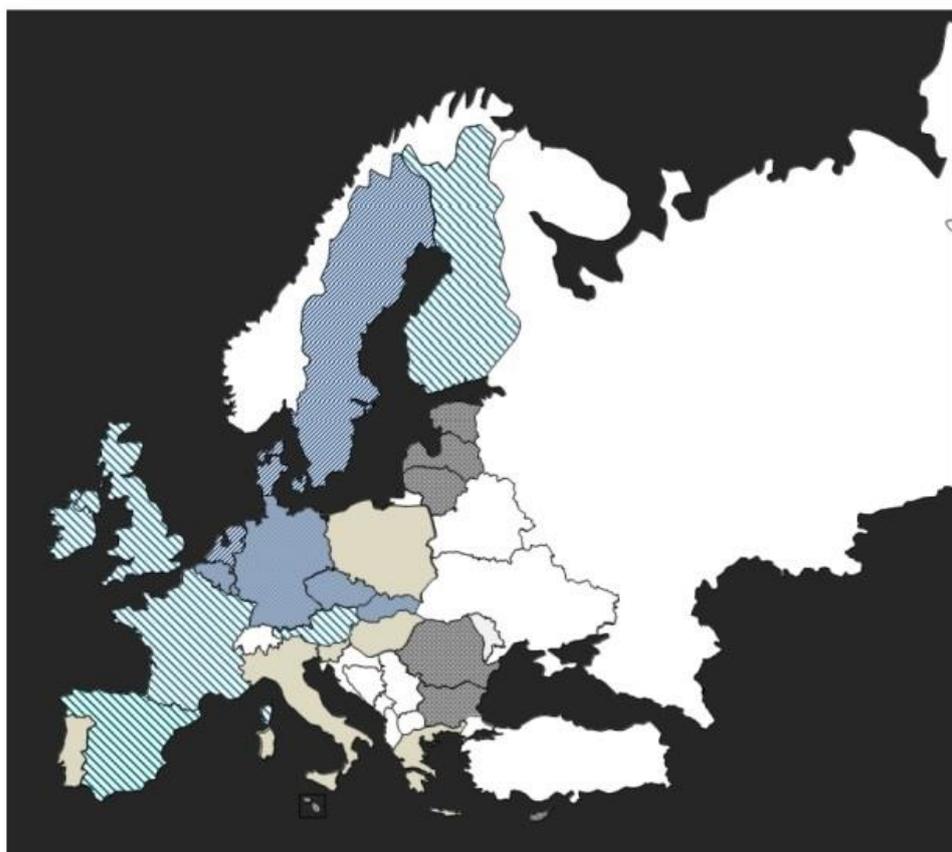
The availability and relevance of services varies a lot across the EU but remains insufficient overall

Countries tend to organise their Long-Term Care (LTC) system in very different ways, one of the most important differences being the role of the state in funding and organising LTC versus individual responsibilities (European Commission, 2014). As noted by Courtin, Jemai and Mossialos (Courtin E., 2014), policies for supporting informal carers are often at an early stage of development and are very unevenly implemented across member States, with some entailing effective support systems for informal carers while others are only beginning to pay attention to the issue.

On average, respondents to the Eurocarers survey rated the relevance and availability of the support offered to carers at 5/10. The lowest rate (1) was reported by carers' organisations from Bulgaria and Slovakia, while the rate of 7 was attributed by organisations from Denmark, Germany, Ireland, and the United Kingdom. For some countries, more than one organisation responded to the questionnaire. Most often, their points of view were consistent. Nevertheless, for some countries (France, Greece, Italy, Slovenia, and Spain) different organisations gave quite different accounts, reflecting regional differences.

It should be noted that this assessment partly coincides with the typology of EU LTC systems developed by the European Commission as part of its *Staff working document on Long-term care in ageing societies (Social Investment Package)* (European Commission, 2013), inserted below.

Typology of LTC systems in the EU27: Spatial map and legend



Nature of the system	Countries	Characteristics
Cluster A  Formal-care (FC) oriented provision, generous, accessible and affordable	Denmark, The Netherlands, Sweden	<i>Public provision</i> of LTC financed from general revenue allocations to local authorities High public and low private spending on FC Low Informal Care (IC) use, high IC support Modest cash-for-care benefits
Cluster B  FC of medium accessibility Some informal care (IC) orientation in provision	Belgium, Czech Republic, Germany, Slovakia, (Luxembourg)	<i>Obligatory social insurance</i> against LTC risk financed from contributions Medium public and low private FC spending High IC use, high IC support, Modest cash-for-care benefits
Cluster C  FC of medium to low accessibility Medium IC orientation in LTC approach	Austria, England, Finland, France, Spain, (Ireland)	<i>Social insurance</i> against LTC risk financed from contributions or general revenue Medium public and private FC financing High IC use, high IC support High cash-for-care benefits
Cluster D  Low FC accessibility Strong IC orientation in LTC approach	Hungary, Italy, (Greece), (Poland), (Portugal), (Slovenia)	<i>Modest social insurance</i> against LTC risks Low public and high private FC financing, High IC use, low IC support, Low cash-for-care benefits
Cluster E  Rather low FC accessibility Almost exclusive IC orientation in LTC approach	(Bulgaria), (Cyprus) (Estonia), (Lithuania), (Latvia), (Malta), (Romania)	<i>Little social insurance</i> against LTC risks Very low public spending on FC Very high IC use, little to no IC support No or very low cash-for-care benefits

Figure 1a and 1b – Source: European Commission (European Commission, 2013)

Where a formal care-oriented provision of services is generous, accessible and affordable (Cluster A), the support is mostly considered positively through Eurocarers survey (DK, NL, SE). In contrast, in countries where the approach to LTC is almost exclusively dependent on Informal Care (cluster E), respondents give a poor assessment of the system (BG, EE). In countries where a mixed approach is implemented (cluster B, C, D), respondents report varied national contexts: support to informal carers is appreciated in some Nordic countries (FIN), Western countries (DE, IE, UK), but considered as very poor in Eastern countries (PL, HU, SK).

Despite some positive policy developments, the opinion that support to carers remains way under what they actually need was largely shared among the carer organisations that were interviewed. Interestingly, a recent survey among family carers of people with a severe mental illness reveals that nearly half of them would require a significant amount of additional support, and about 9 in 10 need more opportunities to meet and share knowledge and experiences with other informal or formal carers².

Carers' organisations consider that the level of formal recognition of carers is far from satisfactory. This lack of recognition also exists in countries where services are nonetheless fitting but mainly organised around formal care, such as in DK. This call for better recognition of carers is shared by other organisations at European level, such as the Confederation of Family Organisations in the European Union - COFACE (Confederation of Family Organisations in the European Union, 2009).

"Informal carers are not recognised as a distinct group with distinct needs. In many cases, we are viewed as free workforce - and this increasingly happens as public spending is cut - but it is less common for us to be viewed as a knowledge resource, and rarer yet to be seen as a group with its own needs and difficulties (...)" (Carers Denmark, in Eurocarers Survey)

Financial support is the most common type of provision put in place by public authorities (indicated by 21 out of the 36 respondents to the questionnaire). Flexible working arrangements are also possible for 21 respondents but pension credits for care time are reported by only 11 of them.

² The CARING FOR CARERS SURVEY was undertaken in 22 countries and received over 1000 responses, the majority (64%) of which were from those caring for people with schizophrenia/psychosis. See: <http://caringformentalhealth.org/>

Around two thirds of respondents to the Eurocarers survey consider that the following support services are available in their country: information (available for 25 out of 36 respondents), advice and guidance (23), counselling/emotional support (24), respite care (21), quality care services (25), specific support for carers dealing with dementia (24).

Yet, these answers must be nuanced as services may be unevenly provided in rural areas and therefore may be difficult to access depending on the place of residence. Indeed, in some countries, the delivery of services may be decentralised and local/regional authorities play a crucial role. In addition, the austerity measures introduced as a result of the economic crisis tend to put services under threat. The unsustainability of funding for some services, together with a growing demand, was frequently mentioned by consulted carers' organisations (for example in Spain, the implementation of a Law adopted in 2007 allowing for cash benefit for carers has been postponed due to austerity measures).

"Out of 350.000 informal carers, 43.000 were granted support by their respective municipalities in 2013." (The Central Association of Carers in Finland, Eurocarers Survey)
"Some counties/areas have very long waiting lists and only basic support available, and others have a very high level of service and support, in particular if you combine what is available from the State with what is available and provided for by not-for-profit organisations." (Care Alliance Ireland, Eurocarers Survey)

Civil Society Organisations play a key role in the delivery of services

Alongside public authorities, Civil Society Organisations (CSO) are contributing a great deal to the provision of social and health services. Figure 2 below shows, based on Eurocarers survey, how respondents perceive the respective roles of healthcare, social care or education systems (in grey), not-for-profit organisations (in yellow) and the private sector (green) in the provision of support. Organisations were asked to state if a series of supporting provisions were available in their country/region, and, if yes, to specify if it was provided by the health care, social care or education systems, by non-profit organisations or by the private sector.

Generally, across Europe, not-for-profit organisations were commonly reported as the first providers of information, advice and guidance, counselling and emotional support as well as specific support services for carers facing dementia. As a matter of fact, 9 out of the 10 consulted carers' organisations offer support services.

The private sector is also to be considered as a key player, notably through flexible work arrangements for carers. The initiative [“Employers for Carers”](#) developed in the UK, demonstrates that it is possible to work and engage with employers to facilitate reconciliation between professional and caring responsibilities.

Good practices in relation to the provision of effective support to carers build on strong cooperation between the health and social sector, the voluntary sector, the private sector, local authorities as well as carers themselves. CSOs play a key role then to reach out to carers and engage them in the design and implementation of the initiatives, as demonstrated by the evaluation of the National Carers’ Strategy Demonstrator site in the UK (Yeandle S., 2011).

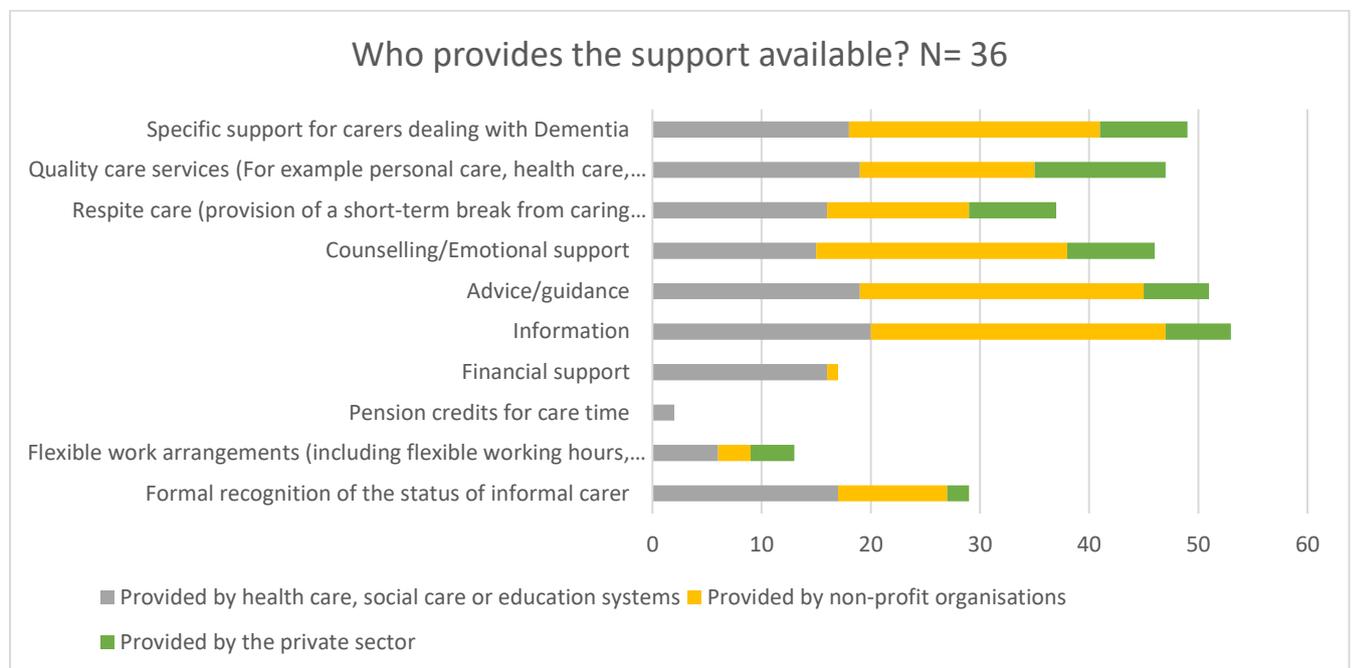


Figure 2 Who provides support? Source: Eurocarers Survey, January 2016.

The graph illustrates the responses given to the questions: Are the supporting provisions listed below available in your country/region? if yes are they provided by the health care, social care or education systems, by non-profit organisations or by the private sector? (N=36)

A moderate use of Information and Communication Technologies

According to the outcomes of the survey, Information and Communication Technologies are being used to offer some services. This is principally the case for *information* (18 of the 36 respondents to the questionnaire indicated that ICT-based solutions were used to provide this service in their country), but also *advice and guidance* (15), *counselling and support* (10) as well as *specific support for carers dealing with dementia* (6).

II -TRAINING OPPORTUNITIES: WHAT IS AVAILABLE, WHAT IS MISSING

This chapter aims to describe to what extent training opportunities are available in the European Union, and how far they are successful in helping carers to manage their role and improve their situation on the labour market.

A – THE STATE OF PLAY

A very fragmented and uneven development of initiatives, largely undocumented.

A growing number of initiatives are being developed on the ground, some of which in the last few years. These are developed by **civil society organisations**, often as the continuation of their informative role, and centred on the needs of carers. In parallel, initiatives are developed **within the health and/or social care sector**, on the initiative of healthcare institutions (hospitals, day care centres) and research institutions (schools of nursing science, faculties of medicine, etc.) which aim both at improving the health status of patients who are discharged after having been hospitalised, and at improving the wellbeing of carers. It was established that training carers does **have a clearly measurable positive impact** on their quality of life, skills and self-reported burden (Haberstroh, et al., 2011) (Eggenberger, et al., 2013), as well as on their ability to cope and resilience to depression (J, et al., 2011).

Programmes developed within by the health and/or social sector (by hospitals, community health services, research centers) are more often subject to published scientific evaluation whereas CSO's initiatives are frequently evaluated in a more pragmatic way (feed-back from participants, attendance...). And yet, carers' organisations agree on the positive impact of training on the quality of life of carers and recommend their development.

Still, training for informal carers remains a largely under-researched field and no comprehensive comparable data exists at European level.

Respondents to the Survey give an average ranking of **4.5/10 when evaluating the learning opportunities available in their country**. Most of them mention learning opportunities or training but still consider that the existing initiatives do not fulfil carers' needs. The situation markedly varies from country to country, with very limited opportunities in Bulgaria and Slovakia, and more developed training opportunities available in Finland, Germany, Italy, Sweden and the UK. As regards other types of support to carers, training may be proposed at national, regional and local level by different types of public authorities as well as by NGOs. In Italy, training initiatives are developed at local level, and may be offered in some areas only. In contrast, in France, policies that underlie training are developed at the national level.

In Sweden, there are different time-limited Group Courses on different topics - often targeted at carers of people with a specific illness, such as a stroke, dementia and diabetes - offered by the health care sector. There are also Courses and Learning sessions focusing on self-awareness offered in the municipality which are delivered by family carers' advocates/advisors. The voluntary sector - i.e. carers associations and patient organisations - offer a range of different Courses for carers, both 'face to face' and online. (Swedish Family Care Competence Centre, in Eurocarers Survey)

What is available?

Learning opportunities are far from being non-existent. As shown in the chart below, at least half of the respondents to the Eurocarers survey consider that learning opportunities exist in their country on the following topics: 'First Aid', 'Self-aid for carers', 'care of older people', 'caring skills', 'coping/managing strategies (e.g. how to deal with the sometimes challenging behaviour of the care recipient)', 'self-awareness and capacity-building', 'lifting, moving and handling', 'learning opportunities specially aimed at carers facing dementia'. Training opportunities geared at the **wellbeing of carers** (e.g. 'exercise and fitness', 'health and safety at work') as well **as communication with the care recipient**, are less frequently available.

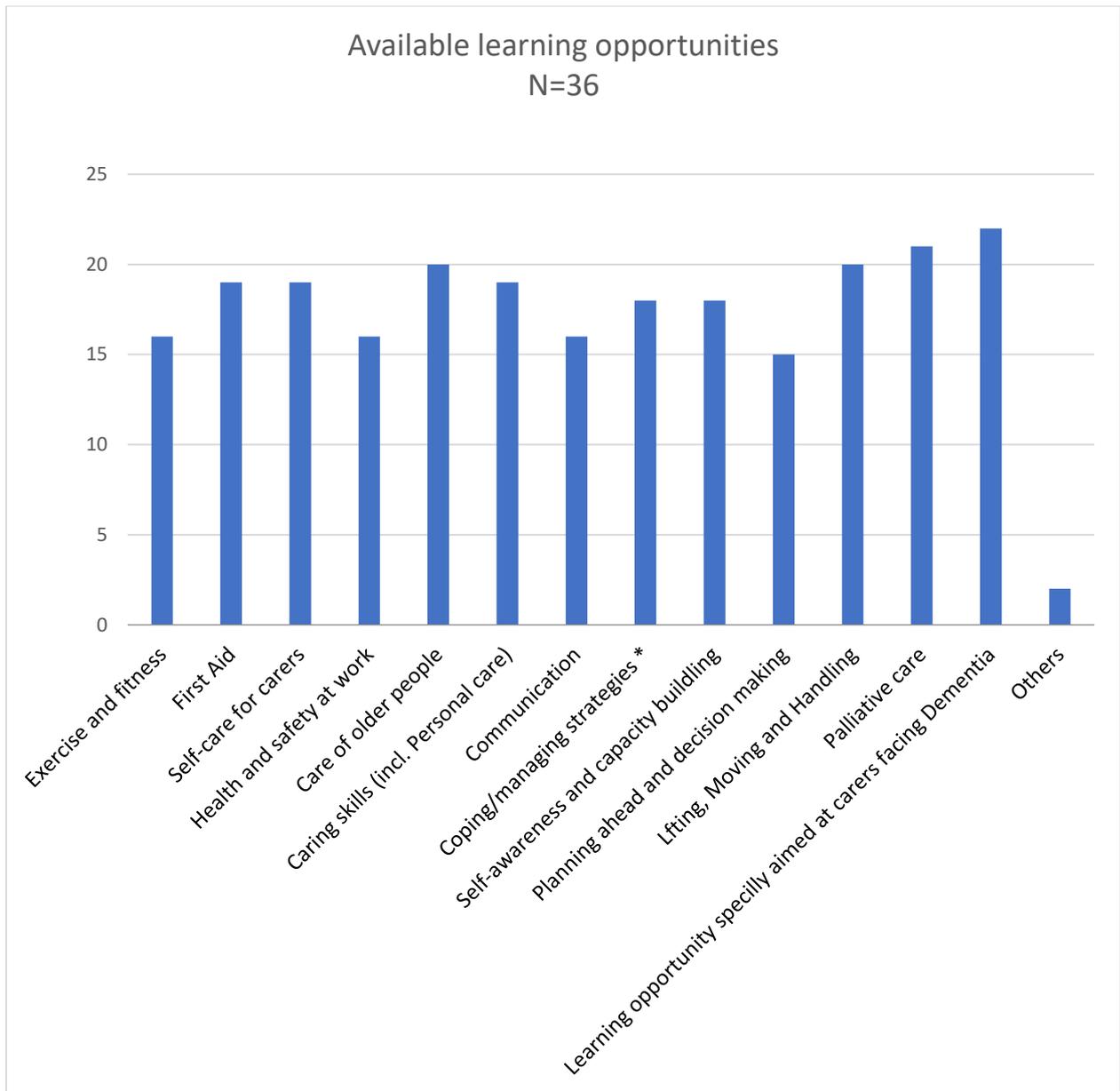


Figure 3: Availability of learning opportunities. Source: Eurocarers survey, January 2016. The figure shows how many of the 36 respondents considered the proposed training content as available in their country/region.

Two main issues: accessibility and take-up.

However, accessibility of the training is generally described as highly problematic. Respondents highlight a number of serious barriers which prevent carers from accessing available training. These obstacles - which can lead to learning opportunities not being taken up to their full capacity- can be summarised as follow:

- **Geographical inequalities** with regards to the accessibility of training: carers living in rural areas do not have as many learning opportunities as those living in urban areas.
- **Lack of information:** too often, carers are simply not aware of existing training. Various CSOs who organise training wish that the information about their programmes could be better disseminated by other stakeholders (doctors, insurances...)
- **Organisational issues:** most carers find it extremely difficult to free themselves from their caregiving responsibilities, as well as from their other family and professional commitments, in order to take part in training courses.
- **Lack of self-identification as carers,** lack of awareness of their role as a carer, implications and the need for training: the fact that caring responsibilities have changed notably due to the growing complexity of diseases and increasing length of the caring period is not well recognised. Carers may consider their role as the natural continuation of their family responsibility and not judge the provision of support or training as needed or legitimate. Family dynamics and representations may also play a key role in preventing carers from taking stock of their responsibility and seeking adequate support. Health professionals interviewed confirmed the difficulty to reach out to carers. Some suggested a stronger focus on carers at the hospital before a person is discharged – which is happening faster than before due to budget restrictions.

Who provides which training opportunities?

Public policies, when addressing the challenges related to the provision of LTC, asymmetrically focus on the development of training. In Austria, a report on dementia was issued by the Social Ministry in 2014, which does not refer to training. In France, training is supported at national level by the public agency (Caisse Nationale de Solidarité pour l'Autonomie) since 2008, as part of a related national plan addressing the challenges linked to Alzheimer's disease.

The role of CSOs

The Figure 4 below illustrates to what extent, according to the respondents of the Eurocarers survey, available training opportunities are provided by health care, social care and education systems or by CSOs. Again, it is clear in the light of collected opinions that the latter play a decisive role. Training is often described as an element in the development

of a community of peers, able to learn from each other's experience and support each other. A feature that carers highly value.

Indeed, scientific literature concludes that training is all the more satisfying when **combined with other types of support**, particularly: rehabilitation programmes (for example post-stroke rehabilitation programmes (Aguirrezabal, et al., 2013), group support (Rodríguez-Gonzalo, et al., 2015), systematic active information and community support (Aguirrezabal, et al., 2013), psychological support (J, et al., 2011) or even part of a comprehensive accompaniment addressing both a transitional care timeline and the emotional journey of the carer (Giosa, et al., 2014). Community healthcare professionals interviewed confirmed the added value of carers networking and learning from their peers.

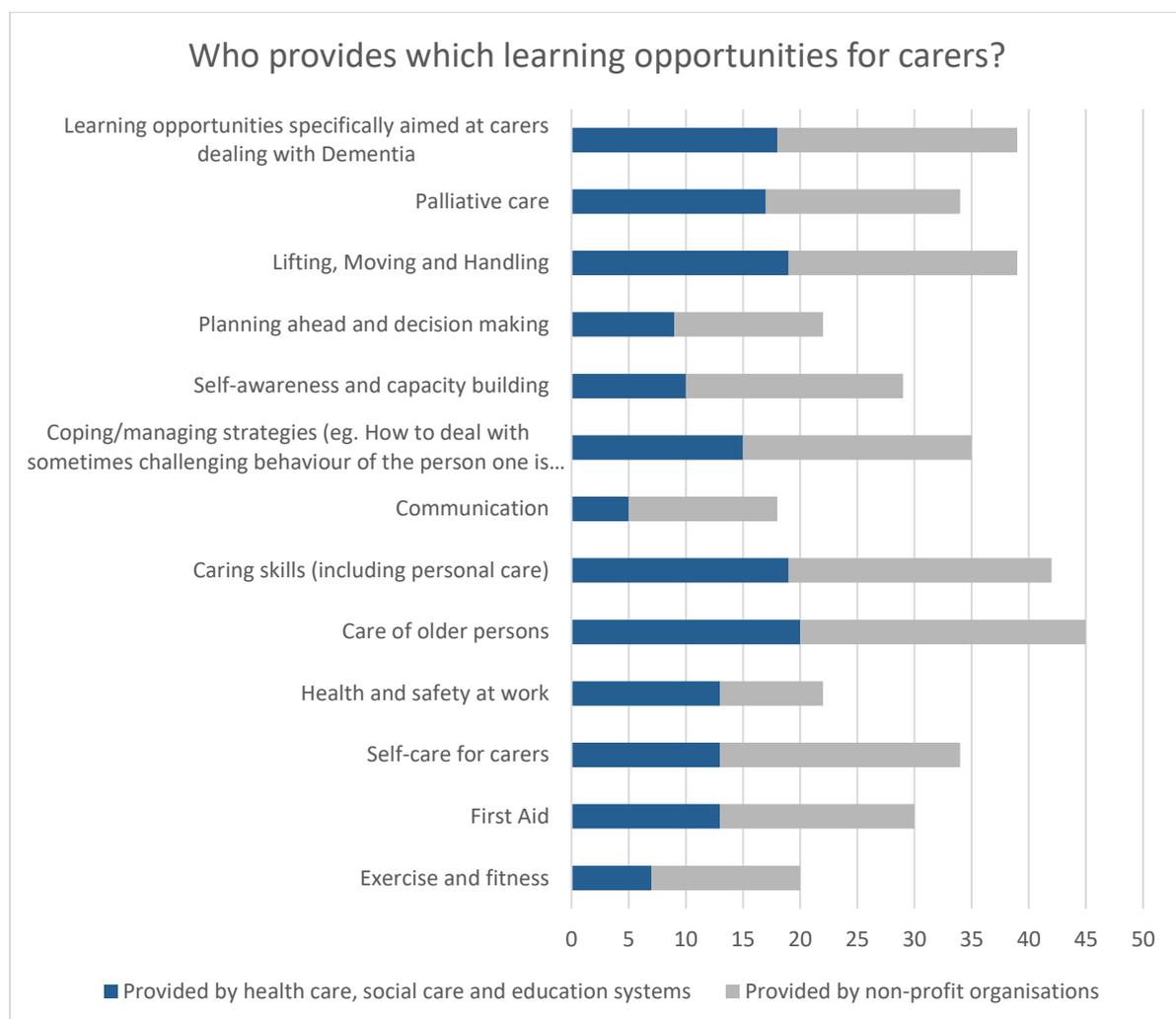


Figure 4: Who is providing the different learning opportunities? Source: Eurocarers survey, January 2016. This graph shows how many of the 36 respondents consider that the listed training opportunities are available and provided by healthcare, social care and education system or non for profit organisations.

B- WHAT IS NEEDED?

Content of the training: what is needed the most?

When consulted about what is completely missing in terms of training, respondents to the survey primarily highlight **transversal skills** that would help carers manage their situation while dealing with their own condition. 'Planning ahead and decision making', 'exercise and fitness' come first, followed by 'health and safety at work', 'self-awareness and capacity building'. An interviewed doctor stressed how carer fatigue can lead to unwanted and unnecessary institutionalisation of the person they care for (see figure 5 below)

'Communication' and 'coping strategies' (e.g. how to deal with the challenging behaviour of the person being cared for) are also considered as non-existent by almost one third of the respondents. Interviewed health professionals confirm the importance of training carers in the field of communication with people suffering from dementia, stressing that it is a key preventative measure against common cases of mistreatment, as well as psychological ill-health among carers.

On an equal ranking, **specific medical skills** such as 'first aid' and 'palliative care' are also deemed missing.



Figure 5: What is missing the most? Source: Eurocarers internal survey, 2016

This graph shows how many of the respondents considered the listed training content as non-existent.

Most often, scientific publications share evidence of the usefulness for the carers to be equipped with specific competencies in order to be able to deliver **quality care**, notably with such contents as disease-specific knowledge, skills needed to maintain the health status of the patient and, if possible, facilitate his/her rehabilitation, symptom management, daily tasks (for example, transferring, bathing and dressing, feeding) and management of emergency situations. These points were confirmed by the health professionals who were interviewed. In line with the needs highlighted in the Eurocarers Survey, they insist on the importance of sharing '**factual information**' related to the

health status of the patient (Hilton, et al., 2013) as well as on developing relevant strategies to improve '**communication with people affected by dementia**', building on the 'expertise of health professionals' (Haberstroh, et al., 2011), and to help carers to manage the stress attached to caring.

Some authors propose to include **more advanced health techniques and skills** in the training programme, in order to support carers and patients at the stage of palliative care: for example, pain management (Valeberg, et al., 2013) or 'mindfulness' as an alternative tool to manage stress (Kögler, et al., 2015).

In addition, several healthcare professionals insisted that training should **contribute to the much-needed improvement in the triangulation between patients, informal carers and health professionals**. Evidence has been provided that including healthcare professionals in the delivery of training also help them increase their knowledge of the challenges faced by carers (Johannessen, et al., 2014). Some initiatives are being taken in this direction (for example the 'Carers friendly pharmacists' pilot project in the UK). The possibility for carers to benefit from a variety of professional supports is too often underestimated: it is important to signpost carers to resources before they are overwhelmed by difficulties. For instance, some pharmacists recommended to raise carers' awareness of the free and accessible services they provide, both to the carers and the people they are caring for (including advice on the safe use of medicine, in case of problems with medications, regarding healthy lifestyles or about the availability of other relevant services).

What is the most efficient timing for a training?

Given the difficulty to reach out to carers, some studies raise the crucial question of **the best timing** for training to be offered and delivered. The immediate period after a stroke (Forster, et al., 2013), and more generally the time of crisis may not be the ideal time to deliver structured caregiver training. This confirms the point of view of interviewed healthcare professionals. Some suggest that, although information on available training is often delivered at the occasion of the hospitalisation of the patient, it may not be the most opportune moment for carers to reflect on their role and decide to take it on board or to acknowledge their role and decide to prepare for it. Information delivered in a more casual fashion (through pharmacies, associations) may be more attractive to them.

While training is often proposed when a patient is discharged home, the added value of **booster sessions**, aiming at reviewing and practising learning at six months' post training programmes is suggested (Ducharme, et al., 2015). The value of offering support at key points of the carer's journey, especially "*when caring arises, at points of change or stress in the caring situation and on a regular basis when caring is long-term and intensive*" has been underlined (Yeandle S., 2011).

Training on communication and stress management of **carers after a relative has been admitted for long-term stay in an institution** is also deemed to be highly useful (Paun, et al., 2015).

The role of ICT in training: from exception to standard?

Today, only a minority of available training is delivered partially or totally online. Yet, a majority of the new initiatives under development build on ICT, and it is debated whether all carers can be targeted via online training resources.

Some argue that one should distinguish between different target groups, depending on the age and the occupational status, with varying expectations as regards the use of internet. From another point of view, the use of ICT must be part of the training itself, and it is possible to develop the use of internet facilities in all groups with a solid ICT support throughout the training. An experiment of e-support design for **older family carers** in Sweden shows that the use of ICT services "contributed to carers competence and promotes feelings of regaining independence and a societal role" (Blusi, et al., 2013).

The potential of online training to retain participants until the completion of the programme is also among the questions that are regularly raised. The University of Stanford (USA) considered the results of an online 'iCare Stress Management e-training programme' as promising, though the high drop-out rate was a concern (Kajiyama, et al., 2013). The **drop-out** rate was also high in a study focused on the guided self-help Internet intervention 'Mastery over dementia' developed in the Netherlands, though the initiative "reached a wide variety of caregivers, including among those aged 75+" (Pot, et al., 2015). The evaluation of the web-based and fully automated psychoeducational program "Diapason" in France reveals that even though participants found the program useful, clear and comprehensive, more dynamic, personalised and social interventions are desirable (Cristancho-Lacroix, et al., 2015).

The interviews with representatives of organisations providing online training tend to reinforce these conclusions: carers adhere more easily to online training opportunities which match their specific needs and are part of a more global offer of services and support, including specific support to access and use this online tool.

Certification? Yes, but....

Existing training pathways, both developed by the health sector and CSOs, rarely include a formal validation process. Hence, respondents generally agree that certification could be of great added value for some carers, notably women confronted to unemployment after long periods of care. Nevertheless, some underlined that certification should not imply too much rigidity in the training provided, thus defeating the purpose of attracting more carers into learning opportunities. They insist that carers need flexibility, and should not be overwhelmed by an exceedingly demanding approach. They suggest that certification may be attractive for certain categories of carers. Indeed, training initiatives are developed that face important challenges, notably the difficulty to coordinate with the education sector, the amount of investment needed, etc. Certification processes have been developed in the UK (see below in III -A Good practices), other initiatives targeted at migrant carers are being developed in Italy.

A more detailed description of available support and learning opportunities in the pilot countries of the TRACK project (France, Germany, and Spain) is annexed to the report (Annex 1).

III- WHAT IS BEING DONE? AN INSIGHT OF RELEVANT INITIATIVES AND PROGRAMMES

A-. CIVIL SOCIETY INITIATIVES

A number of good practices have already been highlighted in the literature [(European Commission, 2013) (European Commission, 2014), see also CARICT-PUBL project described below].

They particularly adapt to the LTC systems to which their country belongs. The voluntary sector is developing a wide range of support services, including specific training. These initiatives can either be localised or widespread at national level. Proposed learning opportunities are rapidly adapting, in line with evolving needs, building on learning from experience. The level of support they receive from public authorities varies a great deal, hence the scale they are operating. Though some of these programmes benefit from an evaluation, this is rarely the case. Formal research, analysing the strengths and weaknesses of these initiatives, is rarely available in the research literature. Though, some of these initiatives may have been validated through more informal evaluation (satisfaction survey amongst participants, participation in the training, reports to managing authorities in the national language).

The seven practices presented below, discussed during the interviews, are presented here since they seem particularly inspiring with regards to the specific challenges addressed by the TRACK project. This chapter will present their main specificities, under the headings “*Objectives and public targeted*”, “*Content*”, “*Features*”, “*Funding*”, “*Validation/certification/ Evaluation*”.

CAMPUS (Italy): online course/ use of European Credit system for Vocational Education and Training

Objectives and target group: CAMPUS online training course targets migrant care workers, Italian women who aspire to work as private paid carers, informal and formal carers, temporary work agencies.

Content: The course consists of 18 multimedia didactic units (each unit lasts approximately 20 min), organized under three headlines (*Role and challenges of care-giving, Knowing the local services and organize caring activities, Help in the daily life activities*)

Feature: Mostly online. However, the e-learning course is often offered in combination with a small number of classroom meetings. A Facebook page is also managed to allow carers to exchange experience and thoughts.

Validation/certification: Each module has a self-assessment test at the end (composed of a multiple choice test for each module, with a threshold of 50% +1 correct answer). The training course is not aimed to provide any official qualification in Italy. However, through an ECVET agreement, the attendance to the course allows for the recognition of credits for the qualification of home-caregiver in Romania.

Funding: The e-learning course can be accessed by individuals (upon payment of a fee) but more frequently a set of accounts is purchased by Municipalities or health and/or social care services who then provide them for free to their users.

Provider: The organisation 'Anziani e non solo' (<http://campus.anzianienonsolo.it/>)

Note that Italy is characterized by strong focus on informal care in the LTC approach, high use of informal care, low support to informal care (Cluster D).

ACTION (Sweden): online support and course, co constructed with carers

Objectives and target group: The ACTION service currently operating in Borås municipality (West Sweden) provides a range of web-based educational caring programmes for carers of older people together with videophone facilities to enable direct peer support with other users and access to a call centre run by professionals in the municipality, together with an in-depth computer training course. The aim of the information and training multimedia programmes is to provide current and topical information on caring in daily life. Carers are informed about the service by their municipality, through information sessions, leaflet, and on-line information.

Content: They cover the following areas: caring in daily life, eating and drinking, incontinence, pressure sores, stroke, dementia, end of life care, benefits and support

services available including assistive devices, coping, planning ahead, relaxation and physical training. The pedagogical approach is based on an empowerment model which seeks to enable carers and older people living at home to gain control of their caring situation by providing them with relevant education, information and support. In so doing, to enhance the preparedness of those carers who wish to continue caring and to increase the predictability of their caring situation. At the same time, to enhance or enrich their caring relationship with their older partner/relative.

Outcomes/Evaluation: In total approximately 500 carers across Sweden have used the ACTION service. They tend to use the programmes a great deal when they first receive the service to gain more information and education about their caring situation. They then re-visit the programmes as their caring situation changes over time so usage varies. Many users express their satisfaction with the caring programmes because they are easy to use and understand and contain relevant, quality assured material. They find it easy that all the material is assembled in one place to save time.

Feature: The educational caring programmes are all available online. The computer training to learn how to use the service is carried out in small groups to enable users to get to know each other. However, it can also be carried out on a 'one to one' basis in the carer's own home depending on their particular situation. The vast majority of users are older spousal carers whom have never used a computer before and those that accept to have the service all complete the initial computer training programme and then have access to regular support.

Validation/certification: Carers do not receive a certificate. However, there is also a comprehensive training programme for staff who work in the ACTION call centre and this programme is certified.

Provider: The service is currently offered by Borås municipality to frail older people and their carers following a needs assessment. The service is delivered via Evry Health Care Systems AB and originated from a University-based small company developed via an EU IV framework research project (1997-2000).

Specific programme for people with Dementia: "Living with Dementia". In ACTION, a specific comprehensive support programme for people with dementia and their carers, called 'Living with dementia' was developed and researched together with people with early stage dementia and their carers. The service contains an easy to use information and education programme called 'Living with Dementia' that contains

information about different types of dementia, common symptoms and range of treatment available. There are video clips with stories from people living with dementia and with carers of people living with dementia. This is supplemented with text giving tips and advice about how best to live with dementia and how to care for someone with a dementia illness. There is a cultural and leisure section which includes popular songs together with a life story section that the person with dementia and their family can work on together. It also includes specially devised cognitive training exercises for people with dementia based on their particular interests such as word games, number games. The service includes an initial eight weeks 'face to face' education programme for people with early stage dementia and their next of kin. These are three hour sessions which include separate sessions for carers and people with dementia together with group time. The sessions include group discussion and computer training. This is then supplemented with the online education material described above. At the same time, users can have access via the videophone to other users and so develop informal support networks (peer support) as well as dedicated professional support via the call centre. The aim being to support the person with dementia and their family throughout the whole caring trajectory. The aim again is based on an empowerment model- to help carers of people with dementia – those who wish to care to gain control over their caring situation, to reduce their anxiety and strengthen their coping resources and resilience and enrich their relationships with their relative with dementia and reduce their worry and uncertainty about the future. During the entire process a user group consisting of people with early stage dementia and their carers participated in the design of the programme.

AMWAHT (The Netherlands)

Objectives and target group: AMWAHT is a training program ongoing in several cities, which aims at empowering migrant informal caregivers.

Content: It trains them to work as a group, as well as to be able to peer support other groups of informal caregivers and supervise them.

Features: This program lasts eight hours per week over ten months. The method follows an informal approach, combining the sharing of experiences and light exercises. The content of the group training is organized around three modules: peer support, networks, and empowerment. The group training is followed by an internship in local care and welfare institutions. According to a personalized approach, AMWAHT searches for the most suitable internship for each trainee.

Outcomes: Participants are enthusiastic about the tailor made approach. The training created a solid mutual trust amongst the participants.

Validation/certification: The participants receive a certificate of participation at the end of the training, which does not have any legal value. When possible and relevant, they are supported towards paid employment.

Funding: Budgets cuts implemented by the government due to the economic situation make it more difficult to plan further trainings.

<http://www.movisie.nl/esi/amwaht-allochtone-mantelzorgers-werken-aan-hun-toekomst>

N.B: Sweden and The Netherlands are characterized by a low use of informal care, high support to informal care (Cluster A).

Training by Family Carers Ireland: formal accreditation of a comprehensive training
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Objectives and target group: Both those aiming at either pursuing a career in the care sector or building on their existing skills or caring experience.

Content: The following contents are proposed: Occupational First Aid, Care Support, Care Skills, Safety and Health at Work, Work Experience, Communication, Care of the Older Person, Inanimate and Patient Moving and Handling, A Palliative Care Approach, Nursing: Theory and Practice, Exercise and Fitness, Activities of Living Patient Care, Anatomy and Physiology.

Features: The following delivery methodologies are incorporated throughout the programme, employing as many varieties within an individual module as would be appropriate to its specific learning objectives:

Directed learning experiences (class/lecture), group discussions/interactions/peer delivery, practical sessions/laboratories using appropriate equipment, resources and/or facilities, role play exercises and/or simulated work environment/experience, self-directed learning including practice-time, preparation, self-directed study, and reflection, field trips,

where appropriate, on the job/work-based training, case studies, one-to-one sessions, online/library research, project work/primary research methods.

All modules are of 5 weeks duration, generally delivered one day per week over the five weeks. Half days or evening courses are organised on demand. Training courses take place nationally, sometimes delivered in Family Carers Resource Centres or other suitable venues. All our tutors have a Nursing and Teaching Qualification coupled with vast experience and expertise in providing care and delivering training to varied and diverse groups. Tutors are available in every county for support and guidance throughout the training programme.

Validation/certification: The modules are component awards leading to the QQI Healthcare Support Level 5 Major Award. There are five mandatory modules and three elective modules required for this award.

It is credit based with some component awards worth 15 credits and some worth 5 credits. 120 credits are required to receive the major award. This award is at level 5 on The National Qualification Framework from which a learner can advance to the next level.

Funding: Funding is provided through the Department of Health, the Health Service Executive and the Department of Social Protection. Funding is not secure and it is variable. The programme also gets funding from The National Lottery, Dormant Accounts, Equality for Women Measure, allowing the training to be free to the family carers.

Provider: Family carers Ireland, the largest group representing informal carers in Ireland. The organisation also runs information days and is piloting a carer mentoring programme. See: <http://familycarers.ie/help-and-advice/training/>.

Outcomes

The training to date has been well attended with learners achieving major awards.

Learners are very positive about the courses:

"I found the course to be very helpful. It helped me be more confident in what I do for the person I care for and myself. "

"I would say I am a different person at the end of the course. More confident, dealing better with my situation and more bright in myself. They say knowledge is power and I have I learned a lot."

"My confidence has improved enormously since I began course. I have learned about so many aids which are available and which will help to improve the quality of the care both

for the care and the person being cared for. Also communication is of vital importance between the carer and the person being cared for.”

Ovet training for carers of Dementia patients (Finland): training based on empowerment, available both on-line and in groups.

Objectives and target group:

Ovet-training is open to all carers irrespective of age, gender or illness/disability of the cared for person.

The training focuses on embracing carers' personal strengths and finding new resources together with other carers.

Content: The training consists of group activities on issues related to informal care, accompanied by introductions/lectures, discussions and individual/pair and group exercises.

The training, contains 8 themes: e.g. caring as part of one's life, legal aspects, support and services for carers and care recipients available, basic care and assistance skills, changes in life induced by caring and the value of peer support.

An additional four-hour-module has been added to the programme

- for working carers (Ovet training for working carers) and
- for carers of people with memory problems (OvetMemory), provided in cooperation with the Alzheimer Society of Finland.

The training encourages carers to ask themselves how they feel, instead of concentrating solely on the wellbeing of their cared for relative. The aim of the training is to increase the potential and options in life of carers.

Features: Duration of 16 hours, face to face though an online application. Online training is offered twice a year.

Certification: none

Funding: The participation in the training is free of charge. It is funded by Finland's Slot Machine Association.

Outcome: Some 1600 carers have participated in the programme since it started in 2010 and the participants have reported having experienced beneficial impacts on their well-being as well functional capacities. After the training, carers tend to take more time for

themselves, feel more empowered, share their thoughts and feelings more openly and know more about the available support services.

Evaluation: Ovet training was developed in a project between 2010-2012, in the framework of a cooperation with the University of Tampere.

Background details of participating carers (in 2010-2012 n=229) were collected, with the following results:

- gender: 83% women
- age: mean age 65,5 years, under 55 years: 15 %
- how long they had been caring: 62 % had cared less than 3 years, 19 % less than 1 year, 16 % more than 10 years
- who they cared for: spouse 64 %, parent 22 %, child with special needs 7 %
- if they were recipients of municipal informal care support: 46 %
- if they were in paid work while caring: 16 %
- what was the principal cause of care need: physical illness, mainly of neurological origin 77%

Prior to the training, participants filled in a form regarding their perceptions of their current life, abilities, skills, thoughts, preferences etc....The same questions were asked one month after the training and an additional follow-up questionnaire and phone interviews were made 3 months after the training. After the training, 94 % of the participants said they knew more about care work than prior to training (42%), 87 % said they knew more about assisting than earlier (37 %), training gave them courage to apply for services (95%-38%).

Provider: Central Association of Carers in Finland together with its 70 local carer associations and partners (municipalities, parishes, other CSOs working with carers and patients) www.omaishoitajat.fi

Caring with Confidence (UK)

Objectives and target group: Develop a free, innovative training for all carers, in order to help them make a *'positive change in their life and that of the person they care for'*. The out of reach carers (including carers from ethnic minorities and socially disadvantaged communities) were targeted.

Content: The programme comprises a range of modules designed to help carers with various support needs (e.g. finance, practical care management, taking a break, accessing support and services). It is based on an empowerment approach.

Feature: The modules were designed to be delivered in small groups by accredited facilitators. They can now be accessed on-line.

Validation/Certification: The path to accreditation has been explored, but not implemented. Challenges were linked to cost attached to certification, and the difficulty to fit into a national system of qualification.

Funding: The programme was initially funded for three years (2008-2010), but then the funded was not renewed, notably based on the relatively high cost per trainee.

Outcomes/Evaluations: A detailed evaluation of the programme has been undertaken by the University of Leeds, which found that the carers who participated in the programme were very positive about it and benefited in a number of ways, including: greater confidence in their caring roles; learning new skills; improved health and well-being; better knowledge of support services; and improvements affecting those they cared for. (Yeandle S., 2012)

Providers: It has been delivered nationwide by selected providers in approximately 25 different sites around England. See: [Caring with Confidence website](#)

N.B: Ireland, Finland and the UK are characterized by Medium to Low accessibility of formal care, High use of Informal care and High support to Informal Care (Cluster C)

Webnurse, Hungary: support on line.
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Objectives and target group: All types of family carers of older people are targeted.

Content: The training touches upon: Daily caring tasks (videos); information about available services - map of services (e.g. LTC institutions, hospitals, pharmacies...); mental health prevention (various topics in the field of mental health), and dietetics.

Features: The training is based on a practical approach and uses mainly videos. Through the website, carers can also benefit from online practical and legal aspects.

Validation/certification: none

Funding: The training is funded by the Hungarian Maltese Charity Service. A difficulty is to fund new developments.

Provider: Hungarian Maltese Charity Service. See: www.webnover.hu

RESje Project, Slovenia: a far reaching informal training programme
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Objectives and target group: The Project aims at combatting stigma attached to dementia and at improving the quality of life of people facing dementia through information, advocacy, awareness raising, as well as help and support to carers and the establishment of a network of volunteers. It is aimed at all informal carers and relatives of older people.

Content: Practical advice on how to maintain a healthy and active life in old age, before and with dementia or Alzheimer's disease.

Features: Training is delivered through interactive informal workshops by experts and volunteers from the organisation.

Validation/certification: None/

Evaluation: The programme started in 2004 and was positively evaluated by the Social Chamber of Slovenia in 2015. The fact that it is proposed by a well-known organisation, gathering more than 500 organisations and clubs of retired people in the country, helps to reach out to a wide audience (52 workshops were held with 751 participants in the past 5 years). The project has been presented in a morning programme on the Slovene National TV Channel.

Funding: mix of thematic calls and donors.

Provider: ZDUS, a non-governmental organisation of retired people, which is the largest membership organisation in Slovenia.

<http://resje.zdus-zveza.si/>

N.B. Hungary and Slovenia are characterized by high use of informal care and low informal care support (Cluster D).

B- TRANSNATIONAL PROJECTS

Whilst the primary responsibility for the provision of Social Protection and LTC lies within the Member States, the EU has been trying to find common ground for cooperation and action in order to address the challenges posed by the ageing of our societies. The decisive role of informal carers - as well as the need to better support them, notably through training - has been identified as part of strategies to reduce the gap between long-term care needs and provision and ensure quality long-term care [(European Commission, 2013) p.15 and (European Commission, 2014) p.57-58, 63].

The channels for EU action on the topic are the following:

- Mobilising Structural Funds to support capacity building for LTC and boost age-friendly environments,
- Improve the knowledge and data, and
- Initiating cooperation between Member States through specific programmes and projects.

EU policies and services in the fields of Employment, Social Affairs and inclusion; regional development; research and innovation; Communications Networks, Content and Technology all seek to contribute to this action. Some of the recent or ongoing European cooperation projects, which are presented below, are particularly relevant to the TRACK project.

Project highlighting good practices, including training for carers

INTERLINKS Health systems and long-term care for older persons in Europe: Modelling the INTERfaces and LINKS between prevention, rehabilitation, quality of services and informal care (2008-2011)

This project, funded under the Seventh Framework Program in Health Research, involved 16 research centres and universities from 14 European Member States. It provides a framework allowing to describe, compare and analyse long-term care provision systems

from a European perspective. It proposes policy recommendations likely to ensure the innovation which is necessary to address the challenges of long-term care. Some learning is of particular interest for the project TRACK:

- Long term care provision should be based on values ([The European Charter of the rights and responsibilities of people in need of long-term and assistance](#), and the [European quality framework for long term care services](#), both elaborated through European projects, can be used as references)
- Long term care is an emerging area for social investment, culture of innovation should be encouraged, involving all stakeholders,
- Investment in long-term care will serve to realize saving in healthcare;
- the provision of long-term care should be better coordinated and centred around the person, the divide between healthcare and social care systems should be overcome;
- Adequate support to informal carer is part of this investment, and should be devoted adequate funding.

See: <http://interlinks.euro.centre.org>

CARICT-PUBL

Publishing and maintaining a directory of ICT-enabled services to support carers (2012 – 2014). The project has investigated the potential impact of information and communication technologies (ICTs) on formal and informal carers by looking at experiences from a number of Member States. It notably documented that the burden of carers can be substantially eased by offering access to training about health. The project was coordinated and funded by the EU Joint Research Centre and carried out by the Italian National Institute of Health and Science on Ageing (supported by Eurocarers and Ilikecake Limited).

<http://eurocarers.org/carict/index.php>

This project published an online directory of **ICT-enabled services** for informal carers to ensure the dissemination of existing good practices and to raise awareness about them among end-users (i.e. carers and older people) and stakeholders. This directory presents services provided online (range from monitoring health conditions, platforms of networking, platform for networking and peer support, help online...). A series of these initiatives include a training component:

- [Ser cuidador](#) (Spain), is an organisation who provides online information, training and exchange for formal and informal carers;

- The Fundación Alzheimer España (Spain) offers different services to people suffering from Alzheimer and their formal and informal caregivers, in particular an online platform (Moodle) to develop and deliver trainings;

- [Caring with Confidence](#) (UK) is a nation-wide programme responding to the most pressing needs of carers;

Two of them include a certification:

- [Elderly Care Vocational Certificate](#) is an e-training programme for formal, informal and migrant carers of older people in Cyprus, Greece, Lithuania, Spain and Hungary aiming at vocationally training them to achieve the "Elderly Care Vocational Certificate" in the Health and Welfare educational field. The training uses the existing e-learning curriculum developed by the LdV ECV project (www.ecvleonardo.com in 2005-2007) supplemented with practical experience at elderly care providers and covers different care aspects both theoretical and practical.). See also detailed description on [Interlinks Website](#)

- [The ODL \(Open and Distance Learning\)](#) initiative offers long-distance training schemes for formal carers via 120 interactive digital resources and individual programmes on the use of ICT and ODL for people who lack ICT skills. Initiative was run by IPERIA from 2003 to 2014.

[DISCOVER Skills for Carers](#)

DISCOVER Skills for Carers is an online social network created through a European project, offering information, advice, guidance and training to support the wellbeing of carers and to develop their digital skills

INNOVAge project (2012-2015)

INNOVAge aimed to help older people to live independently for longer in their own homes by increasing their autonomy and by emerging of new 'technological supply chains' associated with new developments like independent living and eco-innovation, with a valuable contribution to minimize environmental impact of elderly daily life activities. In the continuation of this project, the online platform **INFORMCARE** is offering to carers, in their own language, information and advice (through texts and short videos, on the Themes "Coping with caregiving", "Family reconciliation", "Work reconciliation", "Staying active" ...)

as well as useful contacts and interactive tools to communicate with other peers, exchange experience and provide mutual support. See <https://www.eurocarers.org/InformCare>

Projects developing learning tools for carers

EU CARERS project (2007-2009)

The EU CARERS project (2007-2009) funded under the Leonardo da Vinci EU programme designed the content of a basic face to face training for informal carers and made available training material in 6 languages (English, French, Spanish, German, Polish, Lithuanian)³. A training guide and 6 modules for a total duration of 60 hours were created on the following topics:

- What is Dependence? (20 hours)
- Being a Carer for the Elderly with Dependence (8 hours)
- Being a Carer for those with Severe Mental Disorder (8 hours)
- Being a Carer for the Elderly with Intellectual Disabilities (8 hours)
- Being a Carer for Children with Dependence and Disability (8 hours)
- Toolbox for Carers (8 hours)

The project was coordinated by the University of Vienna (contact: Germain Weber, germain.weber@univie.ac.at)

TranfeRING support for caregivers (2009-2011)

This project, funded under the Leonardo da Vinci EU programme, aimed at supporting the group at risk constituted by caregivers, overall immigrant people employed and unemployed, in the activity of permanent learning and support activities devoted to elderly people affected with dementia.

“Ring” has given them an innovative structured educational product that provides competences on the theme of aid and supportive relationship. The educational products are based on learning from experiences and competences. A kit of three tools has been produced

- A psycho-educational programme of 6 modules transmitting techniques for improving the emotional well-being of the caregiver of the person facing Dementia, through relational strategies and models of cognitive restructuring.
- a booklet "Guidelines for Caregivers", providing information to caregivers about the different forms of dementia, the course of the illness, and practical indications regarding care and support at the end of the patient's life.
- a DVD used as teaching support in training for caregivers containing film clips on the subject of care-giving.

http://www.comune.torino.it/pass/php/4/ring_en.php

The European Skills Training and Reskilling on Dementia (STAR, 2010-2013)

This project, supported by the Lifelong Learning European Programme, comprised experts from the domains of education, technology, and dementia care from 6 countries (the Netherlands, Sweden, Italy, Malta, Romania, and the United Kingdom). It created an educational platform with associated methodology and content for improving the skills of carers (either professional or informal) for people with dementia. Carers can join online communities.

Modules are proposed on the following themes: *What is dementia? Living with dementia; Getting a diagnosis and why it is important; How adaptation and coping influence behaviour and mood; Being a carer; Practical difficulties in daily life and how to help by best practice; The emotional impact of dementia and support strategies; Positive and emphatic communication; Emotional impact and how to look after yourself.*

The STAR training portal was evaluated in a randomized controlled trial among informal caregivers and volunteers in addition to professional caregivers (N=142) in the Netherlands and the United Kingdom. The outcomes of the study demonstrated that the STAR training portal is a useful and user-friendly e-learning method, which has demonstrated its ability to provide significant positive effects on caregiver attitudes and empathy.

All material is accessible on www.startraining.eu.

CARER + (2012-2015): enhancing ICT competencies of care workers

The European Project CARER+ aimed at supporting care-workers to use ICT. It brought together an interdisciplinary and international team of 14 institutions around the EU. The project created a professional network, as well as training programme and resources for carers.

The overall hypothesis underlying Carer+ project is that care workers and carers are the « missing link » to ensure the integration of digital tools to older people day-to-day. In this sense, the project had a double objective: to offer to care workers a set of digital competences to help elder people and to improve their quality of life, autonomy and safety, and to offer to care workers a set of digital competences to enhance their employability and their professional development. To do so, the project developed a digital competence framework, a training programme and a distance learning platform to be accessible mainly via tablet and NFC tags, coupled with a professional network. The project involved almost 500 people, 250 carers and 250 care recipients from 5 countries. Over 70% of carers claimed they would use a tablet device in their caring practice in the future and a majority confirmed that the quality of life of the older people was improved. All the results are available at the website portal or upon request: [www.
http://www.carerplus.eu/](http://www.carerplus.eu/).

RHAPSODY (2014-2017)

Rhapsody is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The main goal of RHAPSODY is to improve care for people with young onset dementia **by supporting their carers. The project will create an educational, web-based, interactive e-learning programme which is tailored to the needs of this particular group of people.** Eight partner institutions from six countries – France, Germany, the Netherlands, Portugal, Sweden and the United Kingdom - are joining their efforts. The research teams represent academia, industry as well as a patient and carers advocacy organisation. The e-learning programme is being currently designed. In a first phase, group interviews have been conducted with informal carers in each participating country, during which participants were asked about their care needs and their thoughts about an online program. The results show that carers find the medical information about YOD is a lot less important than information about how to deal with challenging behaviours and obtaining practical information for day to day living.

See: <http://www.rhapsody-project.eu/>

WEDO2

The WEDO2 project comprises [an informal network](#) aiming to promote quality long-term care services in Europe, the 'WeDO partnership'; a former European project called [WeDO \(2010-2012\)](#), co-financed by DG Employment and Social affairs of the European Commission under the call for proposal for a Pilot project on Preventing Elder abuse; a [Quality care training package](#) developed by the European project [WeDO2 \(2013-2015\)](#), financed by the European Commission Lifelong Learning Programme/ Grundtvig learning partnership.

The training package aims at both professional and informal carers. It mainly aims at increasing the capacity of learners to provide quality care, based on older people's rights, and aiming at improving the wellbeing and the dignity of the care recipients, as well as preventing mistreatment. It provides a wide range of tools (pictures, films, quiz, power point presentations, testimonies and examples of good practice ...) as well as guide for the trainer. Providing a very practical approach of the issue of elder abuse, as well as of the rights of older people and the quality care framework, it is organized around three steps: *The vision, EU Rights of older people, What can we do?*

See: www.wedo.ttp.eu

I CARE (2015 -2017)

This project, started in December 2015, is funded under the Erasmus + Programme, and bring together partners from Italy, France, Cyprus, and Greece. It will aim at:

- Offering free Open Educational Resources in different languages (English, French, Italian and Greek to both formal and informal caregivers (home or institution based);
- Developing knowledge, skills and core competences of caregivers. Informal caregivers will be able to develop basic technical skills (for the most widespread diseases i.e. Alzheimer and cancer) and both informal and formal caregivers will develop transversal soft and ICT skills.
- Supporting the inclusion of informal caregivers with lower levels of qualifications, including carers from disadvantaged backgrounds, by equipping them with the necessary knowledge, skills and core competences. All information are available on <http://daissy.eap.gr/icare/en/home/>.

III- CONCLUSION

Although an exhaustive comparative review of available training opportunities for informal carers in the European Union is beyond the scope of this report, the desk and field research undertaken between December 2015 and March 2016, provide the project with relevant references and pointers. The research also highlights the following points, and helps to articulate a series of indications and questions to be followed up during the course of the project.

The state of play

- Despite the fact that a number of public authorities, taking stock of the key role of informal carers in long-term care provision, tend to develop services and policies to support them, **too little comparative data and research is available on the issue.** Besides, learning from other countries' experiences would be beneficial to new initiatives.
- The type and amount of support provided varies greatly across EU countries and regions, depending on the resources available as well as the role given to informal carers in the national and regional social, health and long-term care provision systems. Yet, **the lack of satisfaction expressed by informal carers regarding the support at their disposal seems to be a common feature**, which shows that much more is to be done to meet their needs.
- **Together with public authorities, Civil Society Organisations play a major role in the provision of a continuum of support services for informal carers, including training, building on a much valued peer network.** The private sector is also playing an important role, with the provision of flexible working arrangements as well as the development of a supporting culture towards working carers. Coordination between public and private stakeholders is clearly essential.
- **The added value of training for carers is acknowledged by health and long-term practitioners, researchers, sociologists, policy makers at EU and national level, as well as by carers themselves.** However, training opportunities remain insufficient, inaccessible or irrelevant.
- Beyond the crucial question of time management in carers' daily life, **a multiplicity of obstacles hinders the uptake of existing training opportunities.** The stigma

attached to caring is persistent and an environment that would be supportive to carers is yet to be built.

- In response to the needs and preferences of carers, **training opportunities are being developed, most often at local level, experimenting a diversity of approaches and methods to face similar challenges**: how to ensure quality and efficient informal care? How to effectively support carers? How to improve their situation on the labour market? How to reach the most remote from the labour market? Concerning these initiatives, evidence based evaluation is often lacking regarding initiatives developed by social care sector and CSOs, whereas it is more frequently available concerning initiatives developed by the health sector. In general, comparative research is lacking.
- **Four types of training programmes for carers have been encountered through the research** - each of them addressing more specifically one or more of the challenges mentioned above.
 - Professional vocational training, also open to informal carers willing to obtain a formal qualification;
 - Training developed within the health sector with the aim of equipping carers with the necessary skills to maintain the health status of a patient discharged home, as well as to maintain his/her own health;
 - Training developed by CSOs, in the continuation of their role as information providers, generally free and open to all carers in a flexible way;
 - Training developed by CSOs, specifically targeted to female carers at a disadvantage on the labour market, with the view to improve their situation, characterized by an intense support and the attempt to provide certification.

This latest type of training may seem the most relevant in the objective of reaching out to carers from disadvantaged groups. However, it requires an important amount of investment, and is underpinned by a tension between the necessary flexibility of the training and the certification requirements.

- **Contents and pedagogical approaches may differ sensibly from one initiative to the other**. However, stakeholders agree on the need to develop some categories of competence in particular:
 - Transversal care competences including communication, planning ahead and decision making;
 - Health specific competences related to emergency situations and illness management;
 - Training helping carers to manage their own health condition.

What works?

The research carried out as part of this report has allowed us to identify the following lessons learned regarding the design of a successful learning pathway.

- Training is most efficient when personalised to adapt to the specific profile, needs and preferences of the carer;
- Co-design and participative approaches are needed to ensure that the needs and preferences of carers are actually met and training is taken up;
- Embedding training in a package of various support services (awareness raising, counselling, peer network, respite care) can help overcome obstacles and reach out to carers;
- Some active pedagogical approaches (multi-component training, including group work, online support, active training on skills, information, support, etc.) can be an efficient approach for specific target groups.
- Combining online (for accessibility) and face-to-face training seems to be the best approach. The use of online features can be extended to carers who may not be very familiar with this tool, provided that technological support is offered to them.
- Enshrining training in a Human Rights approach is a prerequisite for ethical reasons but also because it has proved to be an efficient approach, especially in relation to supporting active living.

Challenges ahead

The discussions also revealed a number of tensions underpinning the construction of a training programme for carers.

- What is the role of the carer? While training should equip a carer with the necessary healthcare skills to provide better care as regards the health condition of the patient, medical consideration should not be the only approach to training, which has to be centred on the needs and preferences expressed by carers themselves. A sound cooperation between health institutions and CSOs can help balance these two aspects. Training should not maintain carers in an obligation of maintaining their role, but rather preserving their possibility of choice.
- Who should be the primary target? The project aims at targeting carers from disadvantaged groups, and should be designed to reach out reach out to them, including the hardest to reach groups (such as ethnic minority carers, high intensity carers, young adult carers, those carers of working age who are not currently in paid work...). However, experience of targeting the hardest to reach groups at first implies a massive

investment, given the intensive support needed, which may be difficult to fund. An alternative approach is to target first the carers who are the closest to the labour market and progressively enlarge the audience building on positive outcomes.

- How to ensure the accessibility of face-to-face support, especially in rural areas? The challenges would have to be taken up such a way so that the training is clearly sign posted as well as implemented. This review of some successful practices suggests building on well-developed existing networks, including community health services or civil society organisations.
- Carers need adapted support at various points of their caring journey. While consisting of a clear, simple and attractive proposal, the pathway to be developed needs to address this reality.
- What are the most efficient methods for learning? The review of practices highlights a diversity of pedagogical approaches, ranging from classical information and advice, to more personalised experience sharing and mentoring. The training pathway to be developed will have to fine tune the pedagogical approach, in order to ensure that, despite the national cultural diversities, the interest of participants is captured, their expectations are met and the drop off is limited.
- How to ensure sustainable funding? Over the long term, ways to ensure the funding the rolling out of the training designed during the two years of the project will have to be explored. Experimentations have been confronted with the unsustainability of public funding. The possibility of ensuring the self-sustainability of the training through introducing fees may be explored. Either, the support of public authorities may also be sought. In this respect, though training initiatives are often supported at the local level, a larger scale could offer economy of scale.
- A certification process will need to find a balance between the necessary formalisation of the training and the preservation of the added value of personalisation, flexibility and choice of role, which fit the needs and preferences of the carers.

Beyond TRACK

This state of play as well as the learning and challenges identified confirm the validity of the TRACK project, in terms of the competences and audience targeted, of the approach building on a cooperation between vocational training organisations, health professionals, formal and informal carers, and of the objective of certification.

Though, in light of the challenges identified, more work will be needed beyond the frame of this project, engaging all stakeholders at EU, national and local level, in order to make progress on awareness raising, data collection and exchange of experiences. Importantly, solid legal frameworks will be needed to ensure that sustainable funding is made available to develop training for carers in a consistent way.

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REFERENCES

- Aguirrezabal, Aizpea, et al. 2013.** Effects of information and training provision in satisfaction of patients and carers in stroke rehabilitation. *NeuroRehabilitation*. 2013, Vol. 33(4), pp. 639-647.
- Blusi, Madeleine, Asplund, Kenneth and Jong, Mats Vol 10(3), Sep, 2013. 2013.** Older family carers in rural areas: Experiences from using caregiver support services based on Information and Communication Technology (ICT). . *European Journal of Ageing*. September 2013, Vol. 10 (3), pp. 191-199.
- Confederation of Family Organisations in the European Union. 2009.** *European Charter for Family Carers*. 2009.
- Courtin E., Jemai N, Mossialos E. 2014.** *Mapping support policies for informal carers across the European Union*. s.l. : Health Policy, 118 (1) pp 84-94, 2014.
- Cristancho-Lacroix, V, et al. 2015.** A Web-Based Psychoeducational Program for Informal Caregivers of Patients With Alzheimer's Disease: A Pilot Randomized Controlled Trial. *Journal of medical internet research*. 17(5), May 2015.
- Ducharme, Francine, et al. 2015.** Maintaining the potential of a psycho-educational program: Efficacy of a booster session after an intervention offered family caregivers at disclosure of a relative's dementia diagnosis. *Aging & Mental Health*. 19 (3), March 2015, pp. 207-216.
- Eggenberger, E, Heimerl, K and Bennett, MI. 2013.** Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. MAR 2013. *INTERNATIONAL PSYCHOGERIATRICS*. March 2013, Vol. 25.
- European Commission, 2013.** *Social Investment Package - Long term care in ageing societies , challenges and policy options, Commision staff working document*. Brussels : European Commission, 2013.
- European Commission, 2014.** *The social protection for long-term care needs in an ageing society. Report jointly prepared by the Social Protection Committee and the European Commission*. Brussels : European Commission, 2014.
- Ferrer, Lourdes. 2015.** *Engaging patients, carers and communities for the provision of coordinated/integrated health services: strategies and tools*. 2015.
- Forster, Anne, et al. 2013.** The development and implementation of the structured training programme for caregivers of inpatients after stroke (TRACS). *Lancet*. 382/9910, 2069-2076 December 2013.
- Giosa, Justine L., et al. 2014.** An Examination of Family Caregiver Experiences during Care Transitions of Older Adults. *Canadian Journal on Aging*. June 2014, Vol. 33(2), pp. 137-153.

- Haberstroh, Julia, et al. 2011.** TANDEM: Communication training for informal caregivers of people with dementia. *Aging & Mental Health* . 15(3), April 2011, pp. 405-413.
- Haberstroh, Julia, et al. 2011.** TANDEM: Communication training for informal caregivers of people with dementia. *Aging & Mental Health*. April 2011, pp. 15(3): 405-413. 9p.
- Hilton, Rose, et al. 2013.** Information, support and training needs of relatives of people with aphasia: Evidence from the literature. *Aphasiology*. 27(11), November 2013, pp. 797-822.
- J, de Rotrou, et al. 2011.** Do patients diagnosed with Alzheimer's disease benefit from a psycho-educational programme for family caregivers? A randomised controlled study. *International Journal of Geriatric Psychiatry*. August 2011, Vol. 26(8), pp. 833-842.
- Johannessen, Aud, et al. 2014.** Implementation of a multicomponent psychosocial programme for persons with dementia and their families in Norwegian municipalities: experiences from the perspective of healthcare professionals who performed the intervention. *Scandinavian Journal of Caring Science*. 28(4), December 2014, pp. 749-756.
- Kajiyama, Bruno, et al. 2013.** Exploring the effectiveness of an Internet-based program for reducing caregiver distress using the iCare Stress Management e-Training Programme. [ed.] 17(5). *Aging & Mental Health*. July 2013, p. 544-554.
- Kögler, Monika, et al. 2015.** Mindfulness in informal caregivers of palliative patients. *Palliative & Supportive Care*. 13(1), 11-18 February 2015.
- Milne, Alisoun, et al. 2014.** Psycho-educational support for relatives of people with a recent diagnosis of mild to moderate dementia: An evaluation of a 'Course for Carers'. *Dementia*. 13(6), November 2014, pp. 768-787.
- Paun, Olimpia, et al. 2015.** A chronic grief intervention for dementia family caregivers in long-term care. . *Western Journal of Nursing Research*. Vol 37 (1), January 2015, pp. 6-27.
- Pot, AM, Blom, MM and Willemse, BM . AUG 2015. Volume: 27. Issue: 8. Pages: 1343-1354. 2015.** Acceptability of a guided self-help Internet intervention for family caregivers: mastery over dementia. *International Psychogeriatric*. 27(8), August 2015, pp. 1343-1354.
- Rodríguez-Gonzalo, Ana, et al. 2015.** Efficiency of an intensive program for informal caregivers of hospitalized, dependent patients: cluster randomized trial. *BMC Nursing*. 2015, Vol. 14(1), pp. 78-100.
- Triantafyllou, J et al. 2010.** *Informal care in the long-term care system, European Overview Paper - INTERLINKS European Project*. 2010.

Valeberg, Berit T., et al. 2013. The PRO-SELF Pain Control Program improve's family caregivers' knwoledge of cancer pain management. *Cancer Nursing*. 36(6), November December 2013, pp. 426-435.

Yeandle S., Bennett C., Buckner L., Fry G., Arksey H. 2012. *Evaluating the Caring with Confidence Programm*. 2012.

Yeandle S., Wigfield A. 2011. *New approach to supporting carers'health and well-being: evidence from the National carers'strategy demonstrator sites programme*. s.l. : CIRCLE, University of Leeds, 2011.

ANNEX 1 – FOCUS ON THE PILOT COUNTRIES

Note see a detailed list of training available in France, Germany and Spain in ANNEX 4

FRANCE

The context:

Statistical elements

- Informal and professional carers were 11 million in 2015⁴
- 4.3 million family carers take care of a person over 60 (for daily tasks, financially or morally)⁵
- 47% of family carers also employees⁶
- 90% of the family carers do not recognize themselves as carers⁷
- 39% of the family carers are isolated⁸
- 60% of the family carers are women⁹
- 48% of informal carers have a chronic disease¹⁰
- 55% of carers would have been interested in a training, only 10% already benefited from a training¹¹
- Informal carers devote 6.5 hours each day to their relative¹²

What support to informal carers?

- The 'Allocation Personnalisée d'Autonomie (APA)' is a benefit allowed to elderly people in need of long term care, which can be used for paying a carer.
- A recent law interring into force on 1 January 2016 raises the amount of the APA, recognize a status for the carer, creates a right to respite care, develop the possibilities of care leaves, and includes measures for prevention and technical equipment of housing.

⁴ Baromètre des aidants, Fondation APRIL, 2015

⁵ Source : Enquête Handicap sante DREES 2012

⁶ Source : Survey by Responsage (www.responsage.com)

⁷ Source : Survey by DOMPLUS, 28/01/ 16, « Les aidants, des personnes à l'intégrité menacée. La nécessité d'une démarche préventive » : <http://prioritealapersonne.fr/carrousel/etude-domplus-aidants-necessite-demarche-preventive/>

⁸ Idem

⁹ Idem

¹⁰ Source Enquête Handicap Santé auprès des aidants informels, INSEE, 2008

¹¹ Panel National des aidants familiaux, BVA/ Fondation Novartis, décembre 2009

¹² Study published by France Alzheimer on 18 January 2016 "Etre aidant : une double peine au quotidien »

- The National Agency for the Evaluation and the Quality of Social and Medical Services and Institutions has issued recommendations aimed at health-care professionals on how to support carers¹³.
- The National Solidarity Fund for Autonomy¹⁴ supports training initiatives for carers since 2008.
- The French national association of carers (Association Française des Aidants) has signed a framework agreement with the National Solidarity Found for Autonomy with the aim to implement a learning programme for carers at the national level, between 2015 and 2018. 143 partnerships with local structure roll up the training programme are foreseen. The programme includes 6 modules, 4 of them being optional. An evaluation of first experimental phase has highlighted the positive impact on the life of carers who followed this training.
- 'La Compagnie des Aidants' has developed training modules accessible on line, as part of a model based on an online community of carers.

The point of view of stakeholders interviewed on the issue of training for carers:

Respondents underline the following obstacles for carers to access training:

- Lack of self-awareness, and difficulty to recognize oneself as a carer,
- Lack of time, lack of information and accessible training in rural areas.
- Difficulty to let a professional caregiver or a healthcare professional take over and care for the elderly,
- Difficulty to let go, to get past feeling guilty and take time for oneself...
- The difficulty for some carers to engage with professionals is also pointed out.

Respondents insist on the need for more awareness raising and information to reach out carers.

Concerning the content of the training they recommend to tackle with priority to the following topics: '*Communication with people facing dementia*', '*practical advice on how to perform day to day tasks*'.

¹³ <http://www.anesm.sante.gouv.fr>

¹⁴ www.Cnsa.fr

GERMANY

The context

In Germany, long term care is underpinned by the principle of “care at home prior to residential care”. The majority of people who need long-term care receive either a care allowance or home care in kind.

There is no official data regarding the number of informal carers in Germany.

What support to informal carers?

- Informal carers can be, under certain circumstances, eligible for being insured under the social pension insurance.
- Carers are entitled to unpaid leave from work under certain conditions. They can also reduce their working time.
- The Act to reorient the Long-Term Care Insurance (“Pflege-Neuausrichtungs-Gesetz”) which came into force in October 2012/January 2013 improved the number of benefits. People affected by dementia receive a greater range of benefits.
- In January 2015 a new legislation (the Bill for a Fifth act to Amend Social Code) aimed at improving the benefits attached to dependency and to reform the tool used to assess the needs of a person.

The point of view of stakeholders interviewed on training opportunities.

Globally, training opportunities, together with support services, are available in Germany both online and face to face. They are mainly provided on a non-profit basis and funded by the German long-term care insurance. Yet, during the interview, stakeholders insisted on the following obstacles:

- The lack of time;
- The lack of information about available trainings – especially for people living in the country side –;
- The lack of self-awareness;
- Computer illiteracy
- The fact that carers may find it irrelevant to share about what they consider as private issues with people outside the family. The “Deutsch Alzheimer Gesellschaft” has set up an online course, aimed both at professional and informal people, which is currently undergoing scientific evaluation. They insist as most important in a training the

following contents: information on disease, how to communicate, how to cope. Though, they would consider that teaching daily care implies face to face interaction. The organisation insists on the importance to empower people to use online resources, including training and self-help online groups.

SPAIN

The context

In Spain, mostly for cultural reasons, families consider care for dependent relatives to be their responsibility. Till recently, generations of families living in the same house was the norm. According to the OCDE, Spain has one of the highest proportion of informal carers with 15,3 % of the population reported as providing personal care and help with daily activities. The care intensity is particularly high in Spain with more than 50% of the informal carers providing more than 20 hours a week to care giving.

Though, fall in intergenerational living, the increasing involvement of women on the labour market is likely to impact on the availability of this type of care.

What support to informal carers

The concept of dependency has been given more attention by public authorities in the recent period. The Law on the Promotion of Personal Autonomy and Care for Dependent Persons came into effect in 2007, ensuring the provision of a minimum level of protection and/or financial aid for dependency (home care, long term stay, tele-assistance, cash benefits...). Each autonomous region as well as each municipality, may complement this minimum with additional benefits. Regions are responsible for the evaluation of the dependency level and the needs of a person, the registrations and evaluation of services providers¹⁵. As an example, the Diputación de Jaén for example is contracting two providers for delivering training on demand: the programme is based on a concertation with groups and associations of informal carers. These trainings raise a very good level of satisfaction among participants¹⁶.

¹⁵ Adequate social protection for long-term care needs in an aging society – Report jointly prepared by the Social Protection Committee and the European Commission, 2014.

¹⁶ See www.clece.es and www.macrosad.es

Though, this law seems to fall short of meeting all the needs and expectations of stakeholders. The possibility of benefiting of cash benefit as a family caregiver and to be registered in the Social Security System open in 2007 has been halted by austerity measures. It is currently reopened, though with a number of restrictions. Today, less than 5% of family carers are affiliated to the Social Security System.

The point of view of stakeholders interviewed on the issue for training for carers.

- Comprehensive trainings are available, provided both by public and private providers. Though, obstacles such as lack of time, lack of respite care, lack of IT literacy, distance, prevent carers from accessing them.
- Certificates are delivered by the Regions based on the validation of professional experience of care. Though, as the vast majority of carers are not formally employed, they cannot demonstrate their experience, therefore they can't benefit from this opportunity.
- The most important content to be included in a training would be: how to contain the development of some illness, how to manage the stress and the risks attached to the role of carer, and how to maintain one's quality of life.
- Most of carers face difficulties to access or to remain in employment: training should reinforce their employability and help them to balance caring and working responsibilities.
- Training should be organized in short modules, close to where the person lives, either face to face or on line and match their capacities.
- At the national level, the work of carers should be recognized. At the regional level more budget should be allocated to supporting and training carers.

ANNEX 2 – METHODOLOGY FOR THE PREPARATION OF THE REPORT

RATIONALE

This note presents the methodology followed by the activities implemented under the IO 01 (Desk Research, Field Research and Report writing).

Given the tight schedule these activities had to fit in, desk Research and the field research have been developed simultaneously between December 2015 and March 2016 and complemented each other's. The writing of the report started at an early stage of the research and has been incremental, so that outcomes and hypothesis as regards to the assessment of needs could be shared with partners early enough to allow them to prepare for the next stages of the project (notably the preparation of the focus groups).

DESK RESEARCH

The Desk Research was conducted with the objectives to gather relevant information in order:

- to describe as accurately as possible, the support services, and the training opportunities available for carers, and in particular carers dealing with dementia, in the EU and in the 3 pilot countries in particular (Germany, France, Spain), both from a synthetic point of view and through a detailed analysis of existing trainings,
- To highlight and describe best practices of training for carers that were relevant to the challenges faced by the project.
- To gather information on past and ongoing European projects.

It consisted:

- In the identification of European Commission publications relevant to the project in the **Eur-Lex database**);
- In the identification of EU projects relevant to the project in the **CORDIS database**;
- In a **review of scientific literature**¹⁷. The following databases were searched: Cinahl, Web of Science, PsycINFO and Scopus. Key words used were: training, teaching, education and skills in combination with informal care, family care and caregiving. The Boolean search strategy was used. It is a broad topic and it gave a very high amount of retrieval, several thousand, so the search was limited to studies performed in Europe in those databases where that opportunity was given and titles that contained the words *child* and *student*, (which was many due to the

¹⁷ A review of literature was performed by the Swedish National Family Care Competence Centre

search terms *teach* and *education*), was excluded. 2011-2016 has been the time limit for the search. Some overlapping between the databases appeared and that is named "duplicates". Based on the result 44 articles that could be possibly relevant were identified.

FIELD RESEARCH

A field research was conducted to complement the outcomes of the Desk Research with the following objectives:

- Ensuring a satisfying description of support services and learning opportunities, both at the EU level in general, and at national and regional level for a series of countries - in priority in the 3 pilot countries (Germany, France, Spain);
- Ensuring a satisfying assessment of learning needs as well as support needs in the EU and in priority in the 3 pilot countries, including the role of the healthcare, social care and education systems in the delivery of these services and learning opportunities;
- Gathering qualitative feedback on obstacles and difficulties, as well as an analysis of the elements of success of training initiatives/programmes;
- Bringing together ideas and proposals regarding a useful training pathway (content, format, way of delivery, validation...)

The field research used both quantitative and qualitative instruments.

- ❖ An online survey was circulated to Eurocarers members, and projects partners, mainly composed of closed questions, allowing to draw a description of support and learning needs in the EU from the point of view of carers' organisations and academics. In total 36 organisations answered this questionnaire.

The distribution of responses by country was as follow: Austria (2 responses), France (3), Spain (2), Portugal (1), The Netherlands (2), Sweden (2), Slovenia (2), Poland (2), Italy (2), Denmark (2), Hungary, Germany (2), United-Kingdom (3), Greece (4), Finland (1), Ireland (2), Bulgaria (1), Belgium (1), Slovakia (1).

- ❖ Qualitative information was collected through various channels:
 - the above mentioned survey contained also open questions,
 - short interviews were organised with some respondents of the survey to get a better understanding of their point of view and get more details on the good practices suggested;
 - A series of succinct interviews were also organised with healthcare professionals, other relevant European organisations, and relevant researchers/experts, in order to ensure that all the point of view of all relevant stakeholders were represented.

In total 30 interviews have been undertaken. 19 persons were interviewed individually, 11 at the occasion of a specific workshop organised during an event held by Eurocarers ("Supporting working carers in Europe" Study Visit, 3-4 March, London).

In total, 58 persons were consulted from 20 EU countries and Canada. The following 8 EU countries were not represented among the persons consulted: Croatia, Cyprus, Czech Republic, Lithuania, Latvia, Luxemburg, Malta, and Romania.

(See the list of persons consulted in the Annex 3).

ANNEX 3 - LIST OF PERSONS CONSULTED FOR THE PREPARATION OF THE REPORT

Name	Organisation	Title		Country	
TRACK PARTNERS (*)					
Heidemarie Müller-Riedlhuber	Wiener Institut für Arbeitsmarkt und Bildungsforschung, WIAB	Chair woman	I	AU	
Tina Gusinde	WBS training	International Project referent	Q/I	DE	(2)
Melanie Tocqueville	IPERIA l'Institut	Scientific Director	Q	FR	
Sandrine Leroyer	IPERIA l'Institut	Project manager	I	FR	(2)
José Juan Guzmán	Diputación Provincial de Jaén	Technical Supervisor	Q M I	SP	
INTERNATIONAL EXPERTS					
Kai Leichsenring	European Centre for Social Welfare Policy and Research (member of Eurocarers)	Senior Researcher	I	AU	
Dr Susanne Weiss	European Skills/Competences, qualifications and Occupations (ESCO)/ reference group for health and social care	Expert	I	AU	(4)
Francine Ducharme	Montreal University	Nurse Researcher	ml	CAN	(1)
Judy Triantafillou	Hellas 50+	Primary care physician Researcher	I	EL	(1)
EUROCARERS Members - Researchers					
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Alice de Boer	The Netherlands Institute for social research	Researcher	Q	NL	
Jolanda Elferink	Movisie	Consultant	Q	NL	
Elizabeth Hanson	Swedish Family Care Competence Centre	Nurse Researcher	I/Q	SW	(1)

Valentina Hlebec	University of Ljubljana Faculty of Social Sciences	Researcher	Q/I	SI	
Dr Jolanta Perek -Bialas	Jagiellonian University	Researcher	Q	PL	
Giovanni Lamura	INRCA	Researcher	Q	IT	
Myra Lewinter	Department of Sociology, University of Copenhagen	Researcher	Q	DK	
Lennart Magnusson	Swedish Family Care Competence Centre	Researcher	I	SW	
Andrea Schmidt	European Centre for Social Welfare Policy and Research	Researcher	Q	AU	
Marco Socci	National Institute of Health and Science on Aging	Researcher	I	IT	
Dr Ralf Suhr	Centre for Quality in Care	Doctor	Q	DE	(1)
Anett Maria Trobert	Institute of Mental Health/Semmelweis University and Hungarian Maltese Charity Service	Researcher	Q	HU	
Sue Yeandle	University of Sheffield	Researcher	Q/I	UK	
EUROCARERS Members - Carers organisations					
Hanneli Döhner	Wir Pflegen	Founder	I	GE	
Areti Efthymou	Athens Alzheimer Association	Psychologist/ Day Care Centre Coordinator	Q	EL	(1)
Moira Fraser	Carers Trust	Director of policy and research	Q	UK	(4)
Rob Gardiner	Carers Federation	Deputy Chief Executive	I	UK	
Jane Greenacre	VOCAL, Edinburgh	Carers support and training manager	Q	UK	(4)
Malla Heino	The Central Association of Carers	Project planner	Q/I	FI	(4)
Zoe Hughes	Care Alliance Ireland	Policy and research Officer	Q	IE	(4)

Irina Ilieva	Alzheimer Bulgaria Association	Executive Secretary	Q	BG	(4)
Konstantina Karagiozi	Greek Association of Alzheimer Disease and Related Disorders	Vice President	Q	EL	(4)
Claudie Kulak	La Compagnie de Aidants	President	Q/I	FR	(4)
Florence Leduc	Association Française des Aidants	President	Q	FR	(4)
Marie Lenstrup	Carers Denmark	President	Q	DK	(4)
Marguerite Mormal	Psychiatric nurse Aidants Proches	Vice -President	I	BE	(1) ^o
Alenka Ogrin	ZDUS	Contact person for international cooperation	Q/I	SI	(4)
Paul O'Mahoney	Family carers Ireland	Campaigns researcher	Q/I	IE	(4)
Ivar Paimre	Estonian Carers	Board member	Q	EE	(4)
Benjamin Salzmänn	Wir pflegen	Board member	Q	DE	(4)
Mareková Slavomíra	Civic Association for Sustainable Development of Regions of Slovakia	Vice Chairman	Q	SK	(4)
Madeleine Starr	Carers UK	Head of Policy Development	I	UK	
Anne-Sophie Söderberg	Carers Sweden	Responsible for EC and IACO contacts	Q	SW	(4)
Joanna Szyszkowska	European Care Foundation	Chairwoman	Q	PL	(4)
Marta Torruella / Martha Mackay	Associació de Cuidadors familiars	Member	Q	SP	(4)
Johan Tourné	Ziekenzorg CM vzw	National Secretary	Q	BE	(4)
Katherine Wilson	Employment for Carers	Strategic Manager	I	UK	
Giovanni Zonin	C'Entro	President	Q	IT	(2)
Spyros Zorbas	KINAPSI	Secretary General	Q	EL	(4)

Others professionals (outside Eurocarers)					
Pf. Antonio Cherubini	Geriatría ed Accettazione Geriatrica d'Urgenza IRCCS INRCA, Ancona	Geriatrician Director	I	IT	(1)
Virginie Cottin	France Alzheimer	Chargée de projet	I	FR	
Alain Fougnyes	Former Director for Care and Services-Centrale de Soins à Domicile de Bruxelles	General Nurse Physiotherapist	I	BE	(1)
Dr Nicole Jacquín-Mourain	National Association of Geriatrists and Gerontologists	Doctor	I	FR	(1)
Sabine Jansen	Deutsche Alzheimer Gesellschaft e.V.	Director	I	DE	(4)
Allison Jarvis	National Health Service Lothian	General nurse- Community nursing Programme Manager	I	UK	(1)
Olga Ch. Siskou	University of Athens	General nurse Researcher	I	EL	(1)
Jamie Wilkinson	Pharmaceutical Group of the European Union (PGEU)	Pharmacist Researcher in social policy and public health	I	EU	(1)

(* in addition to Claudie Kulak, (La Compagnie des Aidants), France, and Elizabeth Hanson (Eurocarers, Sweden) consulted as members of Eurocarers.

(1) Healthcare professionals

(2) VET providers

(3) Representative of informal caregivers' association

(4) Representatives of skills certification bodies and institutions

(5) Policy and decision makers

Q: Consulted through Eurocarers' Questionnaire

I: Consulted through an interview

M I: Consulted through an e-mail interview

ANNEX 4 LIST OF TRAINING AVAILABLE IN THE PILOT COUNTRIES

FRANCE

Nom de l'organisme/association	Public	Durée et format de la formation	Financement de la formation	Validation et sanction	Contenus - apprentissages
ASSOCIATIONS					
Association française des Aidants http://www.aidants.fr/images/Fiche_formation_des_aidants.pdf	Aidant non professionnel	Un parcours de formation de 18 heures (6 modules de 3 heures dont les deux premiers sont obligatoires, les quatre autres sont optionnels). L'objectif est la participation des aidants aux modules qui leur correspondent réellement.			Les contenus des modules: 1- Quand la maladie, le handicap ou la dépendance s'immisce dans la relation au proche 2- Être aidant : une posture, des besoins, des attentes et des limites 3-La relation au quotidien avec son proche 4- Trouver sa place avec les professionnels 5 - Comment s'y prendre avec son proche pour les gestes de la vie quotidienne ? 6- Comment concilier sa vie d'aidant avec sa vie personnelle et sociale ?

http://www.aidants.fr/ateliers-sante-des-aidants/283-vous-etes-un-aidant	Aidant non professionnel	Ateliers Santé	Gratuits	3 ateliers : - La santé physique - La santé émotionnelle - La santé sociale (les relations aux autres) + Documentation sur la santé téléchargeables (http://www.aidants.fr/ateliers-sante-des-aidants/290-documents-sur-la-sante-telechargeables-librement)
France Alzheimer et maladies apparentées http://www.francealzheimer.org/la-formation-des-aidants-familiaux/450	Aidant non professionnel : familles, amis, voisins. Aidants qui accompagnent au jour le jour une personne atteinte de la maladie d'Alzheimer ou d'une maladie apparentée, sans recevoir pour cela de rémunération.	14 heures réparties en 5 modules de formation. Les modules se déroulent toutes les 3 semaines	Gratuite	Les contenus des modules: 1- Connaître la maladie d'Alzheimer 2- S'informer sur les aides possibles 3- Accompagner au quotidien 4- Communiquer et comprendre 5- Être l'aidant familial 6- Préparer l'entrée en établissement 7- Vivre en établissement.
Association France Parkinson http://www.franceparkinson.fr/telechargement/832-DEP_INFO_FPARKINSON2.pdf	Aidant non professionnel de personnes ayant la maladie de Parkinson	une demi journée sur la connaissance de la maladie, puis cycle de réunions par thématique	Gratuite	Guide en ligne Information générale sur la maladie, ses caractéristiques, les traitements, l'aide auprès d'un proche malade, l'impact sur les relations, les aides et les ressources.
Fédération nationale des aphasiques de France http://www.aphasie.fr/Plan-de-Formation-des-Aidants.htm	Aidants de personnes aphasiques	Soirée de sensibilisation qui ouvre sur l'inscription à 1 ou 2 sessions de formation + 1/2 journée quelques semaines après	Gratuite	Session de sensibilisation (03:00) : les répercussions psychosociales, cognitives et psychologiques du handicap de communication pour les personnes aphasiques et leur entourage Session de formation "Mieux communiquer" (1,5 jour), Orthophoniste Session de formation "Mieux vivre" (1,5 jour), Psychologue

<p>Génération Mouvement - Les aînés ruraux - Fédération nationale</p>	<p>Aidants (familiaux et proches)</p>	<p>Ateliers de soutien et d'accompagnement composés de 7 séances DVD : décrire les situations connues, proposer les meilleures attitudes, préconiser des solutions de répit</p>	<p>Gratuit</p>	<p>Les thèmes des ateliers:1-La maladie ou la perte d'autonomie : mieux comprendre les troubles et les comportements2-Accompagner la personne aidée grâce à des conseils sur les gestes essentiels de vie quotidienne3-M'informer sur les aides, structures et solutions de répit4-Me préserver et me protéger pour un meilleur accompagnement5-Améliorer ma relation avec la personne aidée en adaptant ma communication</p>
<p>Mutualité Française</p>	<p>Aidants de malades Alzheimer</p>	<p>Cycle d'ateliers et rencontres individuelles</p>	<p>Gratuit</p>	<p>Un cycle se décompose en 6 séances (4 séances collectives et 2 individuelles). - Séances collectives : connaissance de la maladie, partages et échanges d'expériences sur le vécu au quotidien, repérage du dispositif d'aide et de soutien. - Séance individuelle : le formateur organise des entretiens individuels afin d'accompagner la formulation d'un objectif personnel (de répit) exprimés par l'aidant.</p> <p>Programme du cycle: - Séance collective "Comprendre la maladie" - Séance collective "identifier ce qui peut influencer la maladie" - Rencontre individuelle - Séance collective "Communiquer avec son parent" - Séance collective "Développer des stratégies de soutien" - Rencontre individuelle</p>

<p>La Maison des Aidants / Le CIF-AIDANTS</p> <p>http://www.aidesauxaidants.com/artpublic/bibliotheque/CATALOGUES%20DE%20FORMATION/SOMMAIRE%20CATALOGUES%20EN%20LIGNE%202014_2015/SOMMAIRE%20AF%20site%202014.pdf</p>	<p>Aidants Familiaux</p>	<p>29 modules de formation sont proposésLes modules durent de 1 journée à 4 demi-journées</p>	<p>NC -</p>	<p>4 grandes thématiques sont proposées: Etre un aidant familial- L'aidant familial : qui est-il- L'aidant familial et la relation d'aide- L'aidant familial et la prévention de sa santé- Mieux communiquer avec un proche- Gérer ses émotion pour réduire son stress- L'aidant familial et les limites du maintien à domicile- Quelle vie professionnelle pour l'aidant familial- Etre aidé pour devenir aidantAider son proche : les bonnes pratiques- Comprendre le vieillissement et ses conséquences- Les principales pathologies du vieillissement- Accompagner et comprendre la personne âgée- L'aidant familial et les troubles de la déglutition- L'aidant familial et la prévention des infections à domicile- L'aidant familial et la maladie d'AlzheimerL'aidant familial et la maladie de ParkinsonL'aidant familial et la prévention des troubles cutanés : les escarresL'aidant familial et la prévention de l'incontinenceL'aidant familial et la prévention de la déshydratationLes aides : juridiques, financières, matérielles- L'aidant familial et les aides- L'aidant familial et ses droitsL'aidant familial et les mesures de protection juridique- L'aidant familial et les professionnels à son servicePrévention des risques- L'aidant familial et les gestes de premiers secours (PSC1)- L'aidant familial et la prévention des accidents domestiques et des chutes- L'aidant familial : détecter les signes d'alerte du changement de l'état de santé du proche- L'aidant familial et le déplacement du proche en toute sécurité- L'aidant familial et la bientraitance :</p>
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					le rôle de l'aidant- L'aidant familial :rôle et responsabilité dans la prise des médicaments
ORGANISMES DE FORMATION					
Nom de l'organisme/association	Public	Durée et format de la formation	Financement de la formation	Validation et sanction	Contenus - apprentissages
AFORMAC AURILLAC - GRETA NORD ALLIER -Titre de la formation Aidant familial : auprès d'un parent âgé http://www.intercariforef.org/formations/aidant-familial-aupres-dun-parent-age/aformac-aurillac/formation-03_0801479F_51829.html	Aidants salariés du particulier employeur -	20 heures totales	NC -	Attestation de formation	Repérer son activité professionnelle et se situer au sein des autres membres de la famille et par rapport à l`équipe d'intervention. Repérer l'espace de travail et de vie privée et maintenir une possibilité professionnelle dans un cadre familial. Mieux appréhender le rôle et les limites de l'assistant de vie auprès du parent aidé. Comprendre et gérer l'aspect affectif et émotionnel.

<p>GRETA DES COTES D'ARMOR Titre de la formation: Aidant familial auprès d'un parent âgé</p> <p>http://www.intercariforef.org/formations/aidant-familial-aupres-dun-parent-age/greta-des-cotes-darmor/formation-06_1303219F_33714.html</p>	<p>Tous types d'aidant familial</p>	<p>7 heures totales: Alternance d'apports théoriques et d'études de cas ; Travaux de groupe ; Échange et analyses des pratiques en groupe</p>	<p>NC -</p>	<p>Attestation de formation</p>	<p>Valeurs et représentation de la fonction : - désir d'aider, devoir, contraintes - relation aidant/aidé - soutien de l'entourage - quelle stratégie de soins? L'acceptation de l'aide des professionnels - La répartition des tâches avec les professionnels - Comment gérer l'aspect affectif, émotionnel Quels moyens pour sortir de l'isolement ? Reconnaissance sociale, valorisation, distanciation -Solutions de répit Formations</p>
<p>Formell, un organisme de formation spécialisé dans la formation pour les aidants</p> <p>http://www.leguidedelaformation.com/formation/151/comprendre-sa-situation-d-aidant-familial-et-apprendre-a-mieux-la-vivre</p>	<p>Aidants familiaux salariés des grandes entreprises. Les clients de cet organisme de formation sont La Poste, Airbus, Orange)</p>	<p>4 demi journées (4*4h) en présentiel et un suivi via le portail internet</p>	<p>éligible au DIF (Droit individuel à la formation) et "le plan de formation" des entreprises . Prix: 500 euros les 4 jours en présentiel</p>		<p>Objectifs de la formation: Réaliser et accepter sa situation familial - Identifier ses limites liées à l'état de santé de son proche - Eviter l'isolement social - Se réorganiser sans oublier de s'octroyer des plages de temps libre - Découvrir les aides humaines, matérielles et financières à disposition - Concilier au mieux vie professionnelle et vie d'aidant</p>

<p>Groupe Hospitalier Charles Foix - Jean Rostand (94 Ivry sur Seine) Espace Caapa (Conseils & Accompagnement pour les aidants familiaux des personnes âgées)</p> <p>http://www.reseau-memoire-alois.fr/IMG/d%C3%A9pliant%202012%20Plaque%20caapa.pdf</p>	<p>Aidants familiaux dont le patient a été récemment diagnostiqué (maladie Alzheimer ou apparentée)</p>	<p>Durée : 9 semaines 6 ateliers de 02:00 + 3 entretiens individuels de 00:45</p>			<p>Les thèmes des ateliers: - Mieux comprendre la maladie, son évolution et les différents traitements - Aborder les "troubles du comportement" - Améliorer la communication avec la personne malade - S'informer avec une assistante sociale sur les différentes structures et aides vers lesquelles vous pouvez vous tourner - Aménager votre domicile - Aborder la gestion du stress</p>
<p>"Garder le contact" - Hôpital Bretonneau, Paris XVIII°</p>	<p>Aidants de malades Alzheimer</p>	<p>10 séances de 02:00</p>	<p>Gratuit</p>		<p>Séances d'information, de formation et de soutien avec une psychologue spécialisée de la maladie d'Alzheimer</p>
<p>"Entr'Aidants" - Hôpital Broca, Paris XIII°</p>	<p>Aidants de patients atteints d'une maladie d'Alzheimer ou apparentée</p>	<p>Ateliers de 02:00</p>	<p>Gratuit</p>		<p>Comprendre la maladie Conseils pour le quotidien Eviter l'épuisement</p>
<p>"Alzheimer Formation" - Hôpital de jour psycho-gériatrique - Paris XIV°</p>	<p>Aidants de malades Alzheimer</p>	<p>Cycle de 6 ateliers</p>	<p>Gratuit sur inscription</p>		<p>Mieux comprendre la maladie d'Alzheimer Mieux communiquer avec son proche Mieux comprendre et savoir gérer les troubles psychologiques et comportementaux de son proche Mieux accompagner son projet au jour le jour : techniques de prise en charge dans la vie quotidienne Mieux prendre soin de soi pour mieux prendre soin de son proche : prévenir l'épuisement</p>

<p>"Réseau Culture Ville Santé", Paris</p>	<p>Ateliers de sensibilisation pour les aidants</p>	<p>7 ateliers de 02:00 animés par des professionnels des secteurs sanitaire, social, médico-social et culturel Exemples de lieu de déroulement : Musée du Quai Branly, Entraide, Maison Ste Monique, Conservatoire Darius Milhaud</p>	<p>Gratuit</p>		<p>Connaissance de la maladie d'Alzheimer Troubles cognitifs, psychologiques et comportementaux Gérer les troubles Les différentes aides possibles Les activités complexes La vie sociale relationnelle Ressources et limites</p>
<p>Fondation France Répit</p>	<p>Soignants, Travailleurs sociaux, Responsables d'établissement Aidants (bénévoles, aidants qualifiés) : sous réserve d'accord du comité pédagogique</p>	<p>4 modules de 2 jours de novembre à mars + 1 jour d'examen</p>	<p>Frais d'inscription : 1300 €</p>		<p>Les enjeux, les situations et les besoins de répit des aidants Approche thérapeutique et modalités pratiques de soutien aux aidants L'offre de répit en France et à l'international et le cadre administratif Stage pratique obligatoire de 4 jours</p>
<p>CONSEILS GENERAUX ET VILLES</p>					

<p>Conseil général de Lozère – CLIC</p> <p>http://lozere.fr/aider-les-aidants.html</p>	<p>Aidants</p>	<p>Rencontre mensuelle sur 3 territoires (Mende, Marjevois, Langogne) Ateliers de relaxation</p>	<p>Gratuit</p>		<p>Groupe d'expression et de soutien permettant de prévenir l'épuisement physique et psychologique des proches</p>
<p>Conseil général de Bas-Rhin - Espace d'accueil séniors (ESPAS)</p>	<p>Aidants familiaux</p>	<p>Rencontres d'information et d'échanges</p>	<p>Gratuit</p>		<p>Les thèmes abordés :</p> <ul style="list-style-type: none"> - les démences - les relations aidants/aidés : comment organiser la cohabitation lors de la maladie (préserver sa santé, préserver son équilibre, sa qualité de vie), le sentiment de culpabilité, la maltraitance ... - les aides et relais au domicile - les différentes structures d'accueil (Etablissement d' hébergement pour personnes âgées dépendantes, unités protégées, centre de soins de suite et de rééducation (SSR), hôpitaux de jour, accueil de jour...) - la visite des structures : accueil de jour, unités dédiées - les ateliers gestes et postures - la nutrition - les soins palliatifs et la prise en charge de la douleur - l'information sur les mesures de protection et sur les réformes en cours

<p>Conseil général du Nord</p>	<p>Aidants de malades Alzheimer et maladies apparentées</p>	<p>Maison des Aidants Métropole Lille (Plateforme d'accompagnement et de répit pour les aidants familiaux) Formation répartie sur 5 séances de 03:00</p>	<p>Gratuit (y compris l'accueil des aidés)</p>	<p>Séance 1 Présentation de la formation, des participants, de la Maison des Aidants et visite de la structure Séance 2 Comprendre la maladie d'Alzheimer et les maladies apparentées, avec le Dr Meynieu, neurologue. Séance 3 Les aides possibles autour de chez vous, présentation par M. Bachorz du Clic de Lille. Séance 4 Trucs et astuces pour le quotidien, avec l'intervention d'une ergothérapeute de l'Equipe Spécialisée Alzheimer (ESAD) Séance 5 Ressources et limites de l'aidant familial, prendre soin de soi pour prendre soin de l'autre.</p> <p>Autres activités:</p> <ul style="list-style-type: none"> - Entretiens individuels : soutien psychologique, évaluation de besoins, soutien dans les démarches, documentation spécialisée - Temps collectifs de soutien : groupes d'entraide et de partage, mini-conférences, formations, groupe de soutien - Activités de détente et de loisirs : ateliers QiGong, chant choral, initiation à l'informatique, séjours vacaces, sorties
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<p>Maison des aidants - Nantes Entour'âge - Ville de Nantes</p>	<p>Aidants de malades Alzheimer et maladies apparentées</p>	<p>Sessions de formation composées de 6 à 8 modules</p>			<p>Objectif: -Améliorer les connaissances des aidants sur la maladie de leur proche -Favoriser l'accès et le recours aux aides extérieures -Organiser sa vie quotidienne -Améliorer la communication entre l'aidant et son proche -Permettre à l'aidant de prendre conscience de son rôle, de sa place auprès du malade -Permettre à l'aidant de prendre conscience de l'importance de se préserver pour mieux accompagner</p>
<p>Conseil Général de l'Eure - Résaïda 27 – CLIC</p> <p>http://www.eure-en-ligne.fr/webdav/site/eure-en-ligne/shared/publications/pdf/2010/2010%200916%20depliant%20resaïda.pdf</p>	<p>Entourage familial (parent, conjoint, enfant, ...), amis, voisins qui aident bénévolement un proche âgé ou en situation de handicap</p>	<p>Journées de formation Autres actions: - Groupes de rencontres et d'échanges - Temps de répit - Conférences-débats</p>	<p>Gratuit</p>		<p>Thèmes proposés: - Relaxation et prévention du mal de dos - Aides techniques - Gestion du stress - Culpabilité, deuil et accompagnement - Gestes de premiers secours - Prévention de l'épuisement</p>

SPAIN

Name of the organisation	Target audience	Duration and organisation of the training	Funding of the training programme	Validation	Content
ASSOCIATIONS					
Federación de Asociaciones de Alzheimer http://www.ceafa.es/	Non-formal carers				
TRAINING ORGANISATIONS					
Grupo Eulen http://www.eulen.com/es/servicios-sociosanitarios/servicio-prodependencia/	Profesionals and non-formal carers				Offers training projects to public o private organisations on demand
Euroinnova http://www.euroinnova.edu.es/Atencion-Domiciliaria	Profesionals and non-formal carers		19 - 900	Yes	Many diferent matters: Hygiene, foods, home care, telecare, information about Alzheimer illness, psycho-social support, first aids, etc.
CESI http://www.cesi-iberia.com/?page_id=1506	Profesionals and non-formal carers			Yes	
CEASFOR http://www.ceasfor.com/fp-a-distancia/sanidad/1467-curso-de-atencion-a-personas-dependientes-y-geriatria.html	Profesionals and non-formal carers	1 year	750	Yes	Organization of care for persons in situations of dependency. Social skills. Characteristics and needs of persons in situations of dependency. Care and psychosocial support. Communication support. Home-based support. Health care. Hygienic care. Telecare.First aids. Training and labour orientation. Enterprise and entrepreneurship. Workplace training.

CEAC http://www.ceac.es/cursos/salud/atencion-sociosanitaria?c=I10822M1023&gclid=CNDD3p-BgcoCFUm3GwodGJgC9A	Professionals and non-formal carers			Yes	Organize, prepare and control interventions of attention to people and their environment. Develop physical care interventions for people with specific needs. Develop interventions of psychosocial care for people with specific needs. The activities related to the management and operation of the convivial unit. Perform administration, management and the process of marketing a small business within the field of social and health care.
Carpe Diem https://www.formacioncarpediem.com/listadoPacks.do?cat=1	Professionals and non-formal carers	500 hours	192	Yes	Hygiene, feeding, home care, telecare, information about Alzheimer illness, psycho-social support.
Clece http://www.clece.es/				Yes	Offers training projects to public o private organisations on demand
Macrosad http://www.macrosad.es/	Professionals and non-formal carers				Offers training projects to public o private organisations on demand
Supercuidadores http://cuidadores.unir.net/formacion/catalogo-formativo	Professionals and non-formal carers	15 - 80 hours	95-200	Yes	Organization of care for persons in situations of dependency. Social skills. Characteristics and needs of persons in situations of dependency. Care and psychosocial support. Communication support. Home-based support. Health care. Hygienic care. Telecare. First aids. Training and labour orientation. Enterprise and entrepreneurship. Workplace training.

GERMANY

Name of the organisation	Target audience	Duration and organisation of the training	Funding of the training programme	Validation	Content
Landesinitiative Demenz-Service Nordrhein-Westfalen http://www.demenz-service-nrw.de/pflegekurse.htm	for relatives and professional carer	1/2 days	§45 SGB XI		basic knowledge about diseases of old age, forms and stadiums of dementia, main focus: taking care of people with dementia; self-care
Deutsche Alzheimer Gesellschaft e.V., Selbsthilfe Demenz https://www.deutsche-alzheimer.de/angehoerige/seminarreihe-fuer-angehoerige.html	Train the Trainer	8 modules			Help for Helping - providing presentations about dementia
Alma via Pflegegruppe http://www.alma-via.de/angebote-fuer-pflegende-angehoerige.html	informal carers		financed by health insurance		guidance, handling medication, emergencies, information about support options
Pause für Angehörige von Menschen mit Demenz http://www.pause-fuer-angehoerige.de/_project/static/nobrowsersupport.php	informal carers	20 hours	financed by health insurance		information about: diagnosis, progress and therapy, communication, home care, relief for relatives
Demas. Demenz anders sehen. https://www.demenz-anders-sehen.de/	informal carers	15 hours	free		ICT based training for max. 7 participants, content: dementia, everyday tips, communication and handling of people with dementia, stress management
Hochschule Bremen https://pflege.curendo.de/pflegekurse/sign-in	informal carers	33 modules	99,- € , possibly § 45 SGB XI		care process, eating and drinking personal hygiene, self-care