INFORMAL CAREGIVING AND LEARNING OPPORTUNITIES: AN OVERVIEW OF EU COUNTRIES

EXECUTIVE SUMMARY
of the report developed by Eurocarers in the framework of the TRACK project
March 2016
The report “Informal caregiving and learning opportunities: an overview of EU countries” has been prepared in close cooperation with the partners of the project TRACK. It is available on the TRACK website (http://www.eurocarers.org/track/publications).

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For more information, please contact Claire Champeix, Eurocarers, cc@eurocarers.org.
THE TRACK PROJECT

Carers are people of all ages who provide (usually unpaid) care to someone with a chronic illness, a disability or any other long-lasting health or care needs, outside of a professional or formal employment framework. According to recent research, approximately 80% of people requiring long-term care receive their care from spouses, relatives and friends. Carers’ quality of life is generally poorer than the average and being a carer is often associated with poverty, isolation, frustration, ill health, depression, together with significant difficulty to remain on the labour market – as far as carers of working age are concerned.

The report “Informal caregiving and learning opportunities – An Overview of EU countries" provides a baseline for the EU-funded project ‘TRAining and Recognition of Carers sKills’ (TRACK), which aims to develop a new learning pathway for informal carers, likely to improve their situation on the labour market. The project’s goal is to help increase the relevance of Vocational Educational Training provisions and to bridges the gaps that exist in the field of care, through the development of a training programme targeted at informal carers. The project specifically focuses on the following skills: enhancement of independent living and active ageing, specific illness management (e.g. symptoms management) and transversal care competences (such as communication skills, care planning).

METHODOLOGY, SCOPE AND CONTENT OF THE REPORT

This report builds on research undertaken between December 2015 and March 2016, including a review of available literature, a survey conducted among Eurocarers’ members and partners (with the participation of 36 organisations active in the field of carers’ support), as well as an analysis of research and education touching on the care issue. The information gathered in this document provides an overview of the support available to informal carers - especially training resources - and pinpoints relevant publications and concrete initiatives. Nevertheless, given the limited resources available for this project, this report does not intend to provide a comprehensive and detailed review of existing policies and initiatives in existence. This is particularly true since there is a clear lack of comparative research in this area.

The first part of the report gives an overview of the support services targeted at carers in the European Union. It underlines that the provision of these services varies greatly across countries, regions and even municipalities. The second part of the report then focuses on the training opportunities made available to carers and sheds light on a still undeveloped, extremely fragmented and uneven collection of initiatives, which are largely undocumented. The final section of the report presents a range of initiatives at local level, as well as a selection of relevant ongoing and finalised projects at European level, so as to allow project partners to build on previous learnings. Finally, the annexes to the report include country fiches focusing more thoroughly on the three pilot countries (i.e. France, Germany and Spain), on the bibliography as well as on a detailed presentation of the methodology and list of consulted experts.
CONCLUSIONS OF THE REPORT

The conducted research highlights the following points, and helps to articulate a series of recommendations and questions to be further explored in the course of the project.

State of play

- Despite the fact that a number of public authorities, taking stock of the key role of informal carers in the provision of long-term care, tend to develop services and policies to support them, too little comparative data and research is available on the issue. Access to information about other countries’ experiences would nevertheless clearly benefit any new initiatives on the topic.

- The type and level of support provided varies greatly across EU countries and regions, depending on the resources available as well as on 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 should be done to meet their needs.

- Together with public authorities, Civil Society Organisations play the major role in the provision of a continuum of support services targeted at informal carers, including training, building on a much-valued peer network. The private sector also plays an increasingly important role by providing flexible working arrangements and by nurturing a culture of support towards working carers. Coordination between public and private stakeholders appears to be 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 caregiving is persistent and a carer-friendly ecosystem is yet to be developed.

In response to the needs and preferences of carers, training opportunities are being developed, most often at local level, which tend to experiment a diversity of approaches and methods to face similar challenges: how to ensure efficient and quality informal care? How to effectively support carers? How to improve their situation on the labour market? How to reach the carers most remote from the labour market? Concerning these, it seems that evidence-based evaluation is often lacking for initiatives developed by the social care sector and CSOs, whereas it is more frequently available for 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 at 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 at female carers at a disadvantage on the labour market, with the view to improve their situation, characterised by intense support and the willingness to provide certification.

The latter type of training may seem most relevant to reach out to carers from disadvantaged groups. However, it requires a high amount of investment, and is characterised by a tension between the necessary flexibility of the training framework and the certification requirements.

Contents and educational approaches may differ sensibly from one initiative to the other. However, stakeholders agree on the need to develop various categories of skills, in particular:

- Transversal care competences including communication, forward planning and decision making;
- Health-specific competences related to emergency situations and illness management;
- Training aiming to help carers manage their own health condition.
What works?

The research carried out as part of this report has allowed 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 required 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 educational approaches (multi-component training - including group work, online support, active training on skills, access to information, 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 tools can be extended to carers who may not be very familiar with technology, provided that support is offered to them;
- Enshrining training in a Human Rights approach is not only a prerequisite for ethical reasons, it has also proved to be efficient, especially in relation to supporting active living.

Challenges ahead

The research also emphasised a number of tensions that characterise the design of a training programme targeted at carers.

- What is the role of the carer? While training should equip carers with the healthcare skills needed to provide better care as regards the health condition of the patient, the medical dimension should not be the sole dimension taken into consideration. Training should indeed 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 necessarily seek to maintain carers in their caregiving role, but rather empower them to give them choice.
- Who should be the primary target? The project is targeted at carers from disadvantaged groups, and should therefore be designed to reach out to them, including the hardest to reach groups (such as ethnic minority carers, high intensity carers, young adult carers, carers of working age not currently in paid work, etc.) However, previous experience with these groups has demonstrated the need for more massive investment, given the intensity of support required, which may be difficult to fund. An alternative approach is to primarily target those carers who are closest to the labour market while progressively enlarging the audience, once positive outcomes start to emerge.
- How to ensure the accessibility of the support offered, especially in rural areas? The present review of a selection of successful practices suggests that building on existing fully-fleshed networks, including community health services or civil society organisations makes a real positive difference.
Carers need adapted support at various points of their caring journey. While consisting in a clear, simple and attractive proposal, the training pathway needs to reflect this reality.

What are the most efficient learning methods? The review of practices highlights a diversity of educational approaches, ranging from elementary information and advice, to more personalised experience sharing and mentoring. The TRACK training will have to develop an educational approach, likely to pique the interest of participants, meet their expectations and prevent dropout - despite cultural differences across countries and regions.

How to ensure sustainable funding? Project partners will have to explore ways to ensure that the rolling out of the TRACK training programme is funded beyond the end of the project. The unsustainability of public funding has proved a challenge for previous initiatives of the kind. The possibility to ensure the self-sustainability of the training via the introduction of fees may be explored. Alternatively, additional support from public authorities may also be sought. In this respect, although training initiatives are commonly supported at local level, upscaling the programme could lead to economy of scale.

The proposed options for a certification process will have to reconcile the need for formalised training with specific added values such as personalisation, flexibility and selection of role, which meet the needs and preferences of carers.

These conclusions will feed into the development of the TRACK project, notably regarding the use of online training tools, the development of sustainable cooperation between stakeholders and the promotion of a participative approach that includes carers in order to build truly relevant training programmes and ensure success.
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