

## Research Protocol

# Education Program for Carers in Facilities with Neuro Disabled Subjects EPoCFiNDS

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### Abstract

The prevalence of chronic illness and the disabilities they cause are strongly associated with age. According to the United Nations, in most countries around the world, 8-10% of the population has some form of disability. Carers are helping subjects who have severe or profound core activity limitations in the community and hospice facilities. The skills acquired by carers in their caring role are relevant to the competencies required for occupations and qualifications in community, aged care, health, youth, housing and disability support services. With the aging population the number of subjects with neurological lesions living in hospices and long-term care facilities is increased. It makes a strong case to educate carers to help these subjects. There is a lack of evidence on how to design and implement mechanisms such as foundation skills courses and programs to best meet the needs of carers. The goal of Education Program for Carers in Facilities with Neuro Disabled Subjects (EPoCFiNDS), is to create training programs for carers in neurodisabled subjects living in various facilities. In Europe we need to develop educational programs, aimed at volunteers, relatives or any other group of people so that they better organize benefits care for neurodisabled subjects.

**Keywords:** Carers, Aging, Neurodisability, Rehabilitation, Care

## Background

Disability is a complex, evolving and multi-dimensional concept. Disabilities impact on people's lives in many areas, for example in terms of mobility and the use of transport equipment; access to buildings; participation in education and training, the labour market and leisure pursuits; social contacts and economic independence. According to the UN, in most countries around the world, 8-10% of the population has some form of disability. In the European Union the proportion is greater and ranges between 10-15%. In 2030 it will reach about 17% of the world's population<sup>1</sup>. According to Eurostat overall, 36.9 % of the 70.0 million people with disabilities aged 15 and over in the EU-27 in 2012 reported a need for assistance<sup>2</sup>.

The prevalence of chronic illness and the disabilities they cause are strongly associated with age<sup>3</sup>. Ageing may not lead necessary to greater levels of disability in a population

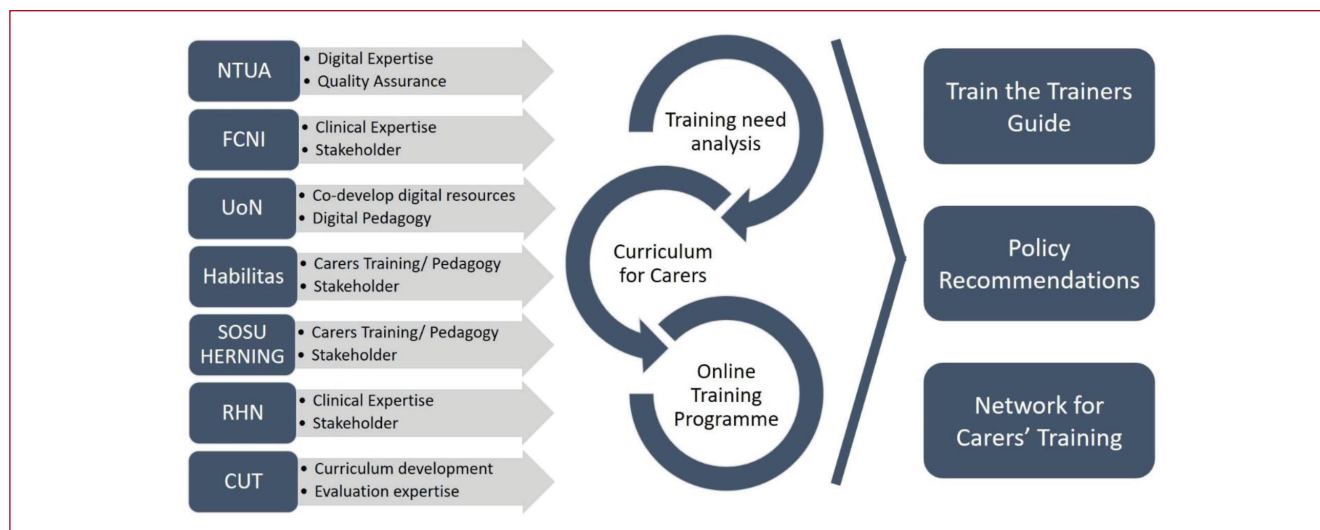
overall. Economic development and scientific improvements in treating should treat illnesses, attenuate disabilities, and lessening the degree of functional limitations. According to statistics, the need for personal assistance is greater for the elderly population, since 45% of the EU-27 request a carer due to difficulties for their personal activities, and in some

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**Figure 1.** EPoCFINDS framework: EU partners' combined expertise enhance skills of carers for neuro-disabled service users.

countries such as Romania (over 85%), Greece (over 62%), Cyprus (55%) this percentage is very high<sup>4</sup>.

People with severe or profound core activity limitations in the community and hospice facilities rely on carers to provide for their personal needs. Carers are helping subjects who have severe or profound core activity limitations in the community and hospice facilities. An informal carer is defined as a family member while a formal carer defined as a paid helper or a volunteer who regularly looks after a child or a sick, elderly, or disabled person<sup>5</sup>. The significance of carers is increasing partially as a result of an ageing population, which is increasing demand for health and community services, including caring<sup>6</sup>.

Carers develop practical skills and knowledge in a range of areas. However, these skills and knowledge were not obtained through training or skills recognition processes. Only recently there are some efforts to define the skills for carers<sup>7,8</sup>. Usually the carers are provided informal training by health care providers; carer support groups and representative associations seeks to address these skill gaps on an as needed basis. The skills acquired by carers in their caring role are relevant to the competencies required for occupations and qualifications in community, aged care, health, youth, housing and disability support services.

With the aging population the number of subjects with neurological lesions living in hospices and long-term care facilities is increased. It makes a strong case to educate carers to help these subjects. A literature review indicated that existing mechanisms to support individuals into education and training have the potential to support carers<sup>9</sup>.

However, there is a lack of evidence on how to design and implement foundation skills courses and effective training programs to best meet the needs of carers.

## Aim

The goal of Education Program for Carers in Facilities with Neuro Disabled Subjects (**EPoCFINDS**) which is an Erasmus+ Project (Code: 2018-1-EL01-KA202-047936) is to create training programs for carers in neurodisabled subjects living in various facilities. Countries such as Greece, Cyprus, Romania etc. need to develop such training programs (theoretical and practical), aimed both at formal and informal carers, so that they enhance care for neuro-disabled subjects.

**EPoCFINDS** objectives include the following: Developing skills for trained attendants; educating carers in modern technologies for neuro-disabilities regarding Activities in Daily Living (ADL); obtaining basic theoretical training on neuro-disabled diseases; recognizing the possible capabilities of subjects with various neuro-disabilities; developing the communication and management skills of caregivers with the neuro-disable subjects; increasing the number and abilities of volunteer carers; create a network of organizations that exchange knowhow and best practices on caring for people with disabilities; create awareness.

Furthermore, EPoCFINDS aims to identify the best practices to train the carers available to everyone, which can be easily tailored to each trainer and group of carers needs. Investment in creating accredited education programs of carers is therefore a necessity for our time. EPoCFINDS envisage that its outputs could be replicable in various caring facilities and for different type of service users.

## Methods

The project was initiated by the National Technical University of Athens (NTUA), which recognized the need

for trained caregivers, caring for people with neuro-disabilities. A lack of data in Greece and in Europe for carers specialized in such fields (i.e. neuro-disability) has commenced a discussion with the Foundation for Care of Neurological Illnesses (FCNI) in order to identify the stakes of such project. FCNI represents the biggest neuro-disability Hospital in Greece, currently providing care for over 180 subjects with various neuro-disabled diseases. FCNI has been treating patients with neuro-disabilities for 125 years, and its name in Greece has been linked to ASYLON ANIATON a philanthropic organization related to excellence and deep knowhow on the subject.

When the need for an evidence-based approach to enhance Continuing Vocational Education and Training (CVET) for caregivers caring for people with neuro-disabilities was established, the NTUA initiated the coordination of formalizing relevant activities. After clearly depicting the needs, scope and objectives of the project, a process for identifying partner organizations with the same objectives, relevant experience and complementary expertise was launched.

After agreement on cooperation, started a collaboration on a work plan, strategy and implementation creating EPoCFINDS framework (Figure 1) in order to achieve the envisaged outcomes.

The EPoCFINDS Consortium is made up of seven partners that have long experience in health care education, training and practice, providing complementary expertise in order to fulfil the aims for the project.

National Technical University of Athens (NTUA) having a deep knowledge on developing Continuing Vocational Education and Training (CVET) programmes, ensures the quality of the produced programme, while its expertise on building digital innovations for healthcare education and training will drive the technical developments of the project.

Foundation for Care of Neurological Illnesses (FCNI) being the largest facility in Greece that care for people with neuro-disabilities could provide clinical expertise on the development of the material, but also access to formal carers, allow the co-creation of the curriculum and the online educational material.

University of Nottingham (UoN) team has a long experience on designing and developing educational resources, namely Reusable Learning Objects, not only for formal healthcare education, but also for the general population including elderly and other high-risk patient groups<sup>10-12</sup>. Using online pedagogy, storyboarding and participatory methodologies and evaluation for the creation of the online material, ensure user-friendliness and involve general public to co-design and testing of the educational material, before it released for use<sup>13</sup>.

HABILITAS Association (Habilitas) was created in 2007 with the aim to contribute to the development of adult education. Habilitas delivers professional adult training and counselling services in social, psychological and educational

projects and programs, allowing access of EPoCFINDS to a large group of formal carers. Similarly, Social & Health Care College, Herring (SOSUHERNING) aims to educate and upgrade staff in the social and health care and educational areas in accordance with applicable laws and regulations and to ensure that their education allow for future developments in society, enhancing EPoCFINDS stakeholder pool.

The Royal Hospital for Neurodisability (RHN) is a residential independent hospital run by a charity. The hospital provides specialist help to patients with a wide range of complex neurological disabilities caused by damage to the brain or other parts of the nervous system as a result of brain haemorrhage, traffic accidents or progressive neurological conditions such as Huntington's disease or motor neuron disease. It includes people who are highly dependent and have complex care needs, people in a minimally aware state, people with challenging behaviour and people needing mechanical ventilation, thus it provides both clinical expertise, but also access to broad range of carers.

Cyprus University of Technology (CUT), is committed to high-quality training and research combined with technological innovation, and it places particular emphasis on training programs within the community<sup>14-16</sup>. Its expertise on curriculum development, but also the expertise on the use of established methodologies to evaluate programmes and training will contribute to the project.

We are aiming to develop a systematic approach on supporting professional carers to acquire and develop professional skills and key competences in order to work with people who suffer from neuro- disabilities. This approach will be the basis on developing training programs for carers throughout different European facilities.

EPoCFINDS will produce innovative intellectual material in terms of educational content. A curriculum for carers in facilities with neuro-disabled subjects, will be created as a result of Training Need Analysis (TNA) engaging carers in the 5 participating countries through questionnaires, interviews and focus group discussions. Based on the competences included in that curriculum, an online training programme will be created accompanied by a Handbook that will act as the guide of training carers tending people with neuro-disability diseases and they are considered two of the major contributions of the project to the European and international community of carers. The e-learning platform will be the key component to allow global access to knowledge and training for carers.

One of the major objectives for EPoCFINDS is to strengthening employability and competences for carers. Hence, we have formed a consortium, consisting of clinical facilities and education foundations, which ensures work-based learning and application of the new acquired skills in practical real-life conditions.

A number of workshops will be conducted in the clinical sites in a total of four different cities in Europe in order to exchange good practices and specific know

how, enhancing the mobility of staff of partners. These provisions will result to specific set of skills much needed in the health care sector, as carers in most cases have a general set of skills, regarding care.

This specialization following EPoCFINDS training programme regarding people with neuro-disabilities will be key to ensure that better and more working opportunities will arise. In addition to this, after the project's end as a long term result, there is a provision for founding a school of carers in Greece providing also on-line learning activities, ensuring more opportunities for continuous professional development for carers.

None of these will be implemented, unless EPoCFINDS management coordinates and support partner efforts, ensuring that general project aims, and results are achieved in the due time and with the planned resources and to effectively and efficiently comply with the contractual and operational obligations with the National Agency, VET/ECVET objectives and the EC requirements.

## Results

We are going to develop new training content that will combine work-based experience with new research developments applied in practice. Training material, a training curriculum and a handbook for training carers on how to work with adults with neuro-disabilities, will be the basis of the training.

In addition, a guide for trainers will ensure the quality and methodology of training occurred. Practical experience and witnessing of best practices will be gained through mobility of the participants. EPoCFINDS aims to train at least 30 trainers in total during five training sessions and at least 50 carers through our e-learning platform. These activities aim to train the trainers responsible to multiply the effects of the project.

EPoCFINDS will release a set of policy recommendations targeting policy makers at EU and International level to further enhance the role of carers in today's society bases on project activities. The policy recommendations will be informed by the project intellectual output and interviews, aiming to highlight policy reform needs on national, EU and international level.

We are going to form a network across different European education and hospice facilities, where knowledge and methodology will be transferred in order to ensure best training methods and practical applications in real life workplace situations. Amongst the seven partners, three are clinical sites that work directly with carers, and two are nursing and carers training facilities. We are expecting multiplying the effects of training by "train the trainers". Through this approach, more people will be in position to spread the knowledge of how to better educate and train a carer.

With well-trained carers we are aiming to have tangible and quantitative results for the subjects with neuro-disability diseases, such as less stress ulcers, less

accidents, better hygiene, less hospital visits, more time out of bed but also qualitative results such as optimism, better quality of life. The results would be registered by each medical facility partner during the evaluation process of the project. In addition, for the trained professionals' carers, we are expecting to have higher employability, better use of modern technologies in neurodisabilities in Activities of Daily Living (ADL), less injuries and better communication with the subject they care for.

These results will be measured according to the evaluation method of the project, but in some of these areas (technology usage, injuries) we expect at least a 30% improvement in short term. Continuous learning will be achieved through e-learning platform and webinars. This platform will promote the exchange information, best practices, problems and solutions and new developments. After its completion we expect that this programme will become the basic approach to train carers in other fields as well, and not just on subjects for neuro-disability but for other form of disability. After its completion, this programme intends the foundation of a school for carers founded amongst partner countries where professional carers, volunteers and family member will be able to be trained on how to care for people who suffer from neuro-disability diseases.

## Discussion

Carers are the canes of people with disabilities. They contribute to their physical and mental health. Their goal is to cover all their needs, such as feeding, toileting, mobilization, and in generally meeting all these priorities that contribute to the socialization of the individual<sup>17</sup>.

Despite the fact that the role of formal and informal carer has started to be recognized as vital in EU Health Systems<sup>18-21</sup>, the EU governments are not investing enough in carers training in order to improve the standard of living for the people they care for.

Currently a few training schemes exist. A notable one is an unaccredited education and training programme by the Australian Department of Social Services<sup>22</sup>. The Care Certificate which designed with non-regulated workforce in mind is an identified set of standards that health and social care workers adhere to in their daily working life<sup>23</sup>. The Royal College of Nursing released the "First Steps for Healthcare Assistants" programme for self-directed learning<sup>24</sup>. The carer role, a role of paramount importance for the European healthcare community, needs additional investment in creating accredited training and education programs of carers; EPoCFINDS is therefore a necessity for our time.

The need for well-trained carers is paramount for the people in need for this care, in order to ensure less injuries, bedding wounds, best quality of care. Training is also important for the carers, since being a carer it is a physically and emotionally draining job. Although their role is important, society does not invest in training and it does not invest in its carers, either through training programs or through

specialized seminars. Consequently, it limits the possibilities and degrades their role. A role of paramount importance for the European community, different EU members have different policies and methods regarding care.

The service of carers is fundamental for people with neurodisabilities since they face difficulty in Activities of daily living (ADL). Training carers across Europe and making training available on techniques and available technology and open to all formal and informal carers (though the program's multiplying events) will mean access to the services and assistive devices needed by people that face the challenge to living with these physically constraining diseases.

The *Education Program for Carers in Facilities with Neuro Disabled Subjects* is an innovative project. Its innovation lies in the fact that for the first time, specific training for carer on neuro-disabled subjects will be systematically designed and implemented in the form of a structured education programme, leading to carers either trained as well as nurses or carers having practical experience mostly for ADL, but not limited to them. Caring for people with disabilities, and more specific caring for people with neuro-disabilities that have very specific needs physically but also emotionally, can be very challenging. Caregivers need to obtain specific training in order to give a better quality of life for their cared ones and to ensure their physical safety (accidents, pains from heavy lifting, etc). In order to do this successfully, a curriculum will be formed in order to ensure the proper structure of the training. This curriculum will refer to the knowledge, competences and skills trainees are expected to acquire, which includes the training objectives they are expected to meet, the subject matters covered and the materials available. In addition, a key element of the innovation of the project is the fact that this training will include real life workplace situations in Hospices with subjects with neuro-disabilities.

Finally, another innovation factor is that the carers is expected to be trained in modern technologies in neuro-disabilities in activities of daily living (ADL) and the coping techniques for both the caregiver and the subject. In order to do this, best practices amongst partners will be showcased, new technologies will be introduced and workshops on real life workspace conditions will take place.

## Conclusion

Giving the fact that there is not specific training for carers, caring for subjects with neuro-disabilities, EPoCFINDS is going to develop this program to facilitate and ameliorate the life of the person suffering of neurodisabilities and enhance the professional development of the carer.

The EPoCFINDS ERASMUS+ strategic partnership consortium consists of the involvement of several researchers, institution, trainers and staff, which under a consistent management and coordination partners individual expertise will ensure a successful outcome.

The intellectual outputs that will be produced as a result

of EPoCFINDS will be in the form of a curriculum, handbook and online educational resources that will be available in EPoCFINDS e-learning platform. The underlying principles of expertise, experience and willingness for furthering the field to assist carers and people with neuro-disabilities for making their life better, will contribute to the success of the project.

Furthermore, the EPoCFINDS ERASMUS+ Strategic partnership will follow a train the trainers approach, providing the relevant material that would allow the best practices of the project to be reused not only to train carers tending for neuro-disability service users, but also to be replicable and reproducible for carers tending other type of service users. In addition, policy recommendations will be released targeting policy makers at EU and International level to further enhance the role of carers in today's society bases on project activities. Last, but not least the EPoCFINDS network of organizations that exchange knowhow and best practices on caring for people with disabilities will be created.

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