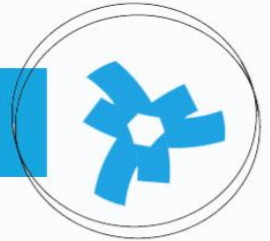




Co-funded by
the European Union

GRANT AGREEMENT
2021-1-NO01-KA220-ADU-000026860

February 2024



STRATEGIES DEVELOPMENT AND IMPLEMENTATION

Project Result N. 3

Index

Introduction	3
Desk Research	3
1. NORWAY	4
2. GREECE	5
3. ITALY	6
4. ROMANIA	7
PURPOSE OF THE STRATEGY	9
1. Objectives	9
2. Key concepts.....	9
3. Findings from the 3 Discussion Forums organized in partner countries	9
Conclusions and recommendations.....	11



Introduction

The 21st century faces an important demographic ageing trend, due to an increase in life expectancy and declining fertility rates in most countries. According to the UN, the percentage of older people (65+) will increase from 9% in 2019 to 16% in 2050. At the European level, the trend of demographic ageing is even more pronounced, it is estimated that 28% of population will be aged 65 or over in 2050, whereas the estimated proportion of the general population 60+ with dementia is between 5-8%. In the context of population ageing an increased prevalence of chronic diseases is observed: older people have an increased number of health problems, which represent challenges to health care and social support. An important health issue nowadays is dementia.

Dementia is a term used to describe any condition where a variety of different brain functions such as memory, attention, thinking, language and personality deteriorate over time. The impairment in cognitive function is commonly accompanied by changes in mood, social behaviour or motivation. Although dementia affects mainly older people, it is not a normal part of ageing. It is a disease of the brain, with deterioration in cognitive function beyond what might be expected from normal ageing.

Dementia affects the ability to perform everyday activities and is one of the major causes of disability and dependency among older people. Its greatest impact is upon quality of life both for individuals living with dementia, and for their family and carers. Dementia is typically associated with particularly intense care needs such as getting in and out of bed, dressing, toileting, bathing, managing incontinence and feeding. The need for support from a caregiver often starts early in the dementia journey, intensifies as the illness progresses and continues until death. Physical, emotional and financial pressures can cause great stress to families and carers, which need to be supported by the health, social, financial and legal systems.

Situation of dementia and care services in each partner country including best practice examples of the implementation of Peer Support Workers' professional figure in dementia care in national contexts

Desk Research

Desk research enabled the PIA partnership to design the structure of a common strategy for enhancing the role and activity of PSW in dementia care. To do this, we collected examples of relevant strategies / policies that can add value to the project objective, and also the national situation of dementia in each partner country.

1. NORWAY

Alzheimer Europe found that the prevalence of dementia in Norway was just under 80,000 people in 2013 (Directorate of Health, 2017). This figure is probably too low because many people live with undiagnosed dementia. Based on WHO figures, there are probably between 80,000 and 100,000 people living with dementia in Norway today.

Prevalence rises sharply with age, from an estimated 1.6 per cent in the 60–64-year age group to 43 per cent among people aged over 90 years (Prince, 2013). Almost every fifth person will die with dementia (Seshadri, 2006). A minority of people develop dementia before retirement. There are probably over 4000 people aged under 65 who have dementia in Norway (Directorate of Health, 2017).

The rises in life expectancy in Norway will more than double the number of people with dementia from 2015 to 2050.

Some action plans and governmental policies are targeting dementia such as Parliamentary decision n. 25 (2005- 2006), offering strategies and concrete measures to address the dementia challenges, the Report IS-1486 issued in 2015 «Forgetful, but not forgotten», the Dementia Action Plan 2015 – 2019, “A good and meaningful day”, and Dementia Action Plan 2020 – 2025 “Living with dementia”.

Among the best practices examples of PSW role at an international level we can mention the PIA-project aiming to create sustainable and competency-enhancing services for people with dementia by finding new ways to involve users and their next of kin in service development (Website PIA-project)

Other best practices on national level include: The use of Peer Support Workers in dementia care to reduce loneliness, contribute to better health and quality of life for persons with dementia and their families (ongoing project). This is a national innovation project in two municipalities in central Norway financed by the Health Department (national). Four Peer Support Workers, two in each municipality, offers individually adapted services to younger persons with pre-senile dementia that still lives at home.

Peer Support Workers as a member of the municipal Memory team (ongoing project),

Another national innovation project is developed in two municipalities in central Norway and the Peer Support Workers work in close collaboration with community nursing services and Memory team. The goal is to test different models and publish a report on how peer support workers can be integrated in the Memory team.

Sterkere sammen | PIA - pionerarbeid i demensomsorgen - KBT Fagskole

Kan erfaringskonsulenter hindre ensomhet blant eldre med demens? - KBT (kbtkompetanse.no)

Erfaringsmedarbeidere i demensomsorgen kan bidra til at folk får bo hjemme lenger - KBT (kbtkompetanse.no)

2. GREECE

There are no adequate epidemiological data on dementia in Greece. However, by extrapolating using data from other countries, ADI calculates the prevalence of dementia in Greece in 2010 to 196,000 people, whereas, according to the latest data from the Greek National Observatory, there are 200,000 people living with dementia in Greece and 400,000 caregivers looking after them. Moreover, it is estimated that in 2030 these numbers will reach 276,000 people and in 2050 365,000 people. These numbers will increase dramatically in the years to come, making dementia one of the most crucial medical, societal, and economic challenges in Greece, as is all over the world.

Recognizing the magnitude of the issue and responding to lobbying efforts from the Alzheimer Associations, in October 2013, the Greek state assigned a working group to develop a National Dementia Strategy. The Ministry of Health set up the National Committee Working Group, which accomplished the National Action Plan for Dementia 2015-2020, by the following decision (ΔΥ1δ/Γ.Π.οικ.108620). This plan includes a series of important axes aiming to registration and classification, prevention, support and treatment.

Currently, the structures providing health care services for dementia in Greece are the following: Memory and Cognitive Disorders Clinics and Psychogeriatric Clinics Special Memory and Cognitive Disorders Clinics (around 20).

There are also some non-profit Alzheimer Associations in Greece such as:

Alzheimer's Associations operating in various Greek cities set up by relatives and caregivers of people with dementia, doctors, psychologists and other health professionals.

Day-Care Centres represent the most integrated services for people with dementia and their caregivers'. These are under the responsibility of Greek Alzheimer's Associations and were implemented under the operational program "Health – Welfare 2000-2006" co-funded by the European Union and the Ministry of Health and Social Solidarity.

Community services like the Open Protection Centres for the Elderly (K.A.P.I.), the Day Care Centres for the Elderly (K.I.F.I.) and the services "Help at Home" provided by many Municipalities of the country offer services to people with dementia and their families' although not specialized ones.



The private Care Units for the Elderly in our country cover a small percentage of the existing housing needs and do not have specialized care for people with dementia. There are only a few private nursing homes specializing in dementia.

Social Benefits for people with dementia: social security covers part of the costs for specific services related to the treatment and movement and cognitive rehabilitation of people with dementia (physical and speech therapy) and for limited periods of time.

The Strategic Planning with regards to dementia is including the vision of the National Action Plan and is has specific social and epidemiological objectives.

Family caregivers/carers of the People with Dementia. Even though caregivers constitute an inseparable role in dementia care, however there is no specific legislation framework for family caregivers as well as professional carers. Dementia care services and health professionals recognize their efforts in dementia care and the fact that they are assumed as the steppingstone in people with dementia care, however, there is no plan based on their needs and support.

3. ITALY

According to epidemiological data from the Italian Ministry of Health, currently the total number of dementia patients is estimated at more than 1 million (of which around 600,000 have Alzheimer's dementia) and around 3 million people are directly or indirectly involved in their care, which also has economic and organizational consequences. According to the same medical body, the greatest risk factor associated with the onset of dementias is age. A really up-to-date official statistical report on the Italian population (ISTAT, April 2023) reports that in Italy the populations balance is negative, one in four Italians is +65 and life expectancy at birth is 82.6 years old.

National Dementia Plan. In Italy, for the social protection of persons with dementia and to ensure the early diagnosis and timely care of persons with Alzheimer's disease, the Alzheimer's and Dementia Fund 2021-2023 was established by Law No 178 of 30 December 2020. The National Dementia Plan (PND – Piano Nazionale Demenza) was formulated by the Ministry of Health in close collaboration with the Regions, the Superior Institute of Health (ISS - Istituto Superiore di Sanità) and the three National Patient and Family Associations. In order to cope with the strong social impact of dementia, in 1999 the Emilia-Romagna Region approved the Regional Project on Dementia (with D.G.R. 2581/99), which gave rise to a network of services, present throughout the region, of specialized Centers (cognitive disorders and dementia centers) in the diagnosis and treatment of dementia, connected to social-health services.

The Third Sector on Dementia Care. Another important player in dementia care is represented by the NGOs, a series of private entities that promote activities of general

interest as well as on issues of dementia. The biggest is Alzheimer's Disease Association (AMA – Associazione Malati Alzheimer) and Parkinson Italia onlus.

Services available for Dementia Care: Integrated Home Assistance (ADI - Assistenza Domiciliare Integrata), Home Assistance Service (SAD - Servizio Assistenza Domiciliare), social vouchers offered to support families who have disabled or elderly people as dependents and who carry out care work (caregiver), meals on wheels, employment and Personal Services Desk (Sportello Occupazione e Servizi alla Persona) as well as temporary admissions for patients with dementia managed by the regional Health Protection Agency (ATS - Agenzia di Tutela della Salute) offering the possibility of short admissions to territorial Nursing Home (RSA - Residenza sanitaria assistenziale) and Integrated Day Care Centers (CDI – Centro Diurno Integrato).

Family (or informal) caregiver. The National Resilient Plan (PNRR - Piano Nazionale Ripresa Resilienza) from 2021 introduces the care plan that includes needs and possible resources for interventions in favour of the non-self-sufficient person. Caregiver legislative recognition, however, has not been followed by the provision of an integrated system of protections and forms of support, as the Italian Minister for disabilities acknowledged in March 2023. Through LRR 2/2014 the Emilia-Romagna Region intended to recognize and enhance the figure of the caregiver. In Italy, the figure of the Peer Support Worker is mainly present in the field of mental health, finding great success and usefulness.

4. ROMANIA

In 2019 Alzheimer's disease was listed as the 6th cause of death in Romania, according to www.healthdata.org/romania. Dementia in Romania has a serious impact: from an approx. number of 270,000.00 – 300,000.00 people with Alzheimer's only 35,000.00 are detected and diagnosed. Unfortunately, a lot of cases are diagnosed very late (Romanian Alzheimer Society, 2015). The diagnose rate of this disease is of only 10-15%. In Romania there are approx. 220,000.00 new cases of mental disorders yearly (National Center for Statistics in Public Health - CNSSP, 2020). According to the same source, for every 100,000 inhabitants there is an incidence of approx. 1,200.00 mental disorders (ibidem).

In Romania Alzheimer's disease is included in a program belonging to the National Health Institution (CNAS) with specific medical classifications. A diagnosed patient can access a specific free of charge treatment following a thorough protocol. Although precocious diagnosis is paramount, a lot of people arrive to their MD in late or very-late stages. In 2013 the Ministry of Labor, Family, Social Protection and Elderly had issued the Order no.2272 regarding the Procedures for the application of the provisions of art. 42 of the

Law 448/2006 regarding the protection and the promotion of the rights of the disabled people.

In Romania there is neither a National Dementia Strategy nor a National Dementia Action Plan. The Romanian Alzheimer Society, an NGO member of Alzheimer Europe, had launched since 2014 an Appeal for a National Strategy on Dementia. Taking into account only the cases of Alzheimer's disease, it was proven that for each person with dementia another 3 or 4 people are involved, leading to approx. 1 million Romanians all over the country dealing with this problem (www.healthdata.org/romania). Prevalence of dementia in Romania was of 1.43% of the whole population in 2018, and the estimated prevalence for the year 2050 will be 2.56% (<https://www.alzheimer-europe.org/dementia/prevalence-dementia-europe>).

National Programs and Useful National Interventions. Some national programs and specific legislation decisions are regulating the interventions of the target group mentioned in this document. The National Plan of Action for Dementia and its Strategy for the period 2014 – 2020 was launched by the Romanian Alzheimer Society together with Alzheimer National Alliance on February 27, 2014, however no legal framework is available. Dementia Care Projects – Partnership Projects with Romanian NGO's. In Romania the NGOs are playing a very important part in raising awareness on dementia. The most important organization is Romanian Alzheimer Society. Romanian Alzheimer Society together with Asociația Habilitas CRFP elaborated the National Dementia Plan for Romania within a POCA project called 'Mental Health – Priority on the Public Agenda!' (2018-2020).

Awareness Campaigns on National Level. In 2019 it was celebrated for the first time, on national level, the International Day of Fighting against Alzheimer's. In 2020 the Association of the Patients with Neurodegenerative Disorders (APAN - Asociația Pacienților cu Afecțiuni Neurodegenerative) launched a call to raise awareness regarding the most susceptible group of people (<https://afectiuni-neurodegenerative.ro/hai-sa-vorbim-despre-dementa/>)

Best practices examples of PSW role. The role of the Peer Support Worker is not known in Romania, and in the field of mental health it is unfamiliar and rarely used. Some projects tried to introduce the role of the Peer Worker in the mental health area like the project Peer2Peer a vocational training course aiming to enable the individuals who have experiences mental issues to become PSW for people diagnosed with dementia, or with other mental ailments (<http://p2p.intras.es/index.php/about>).

PURPOSE OF THE STRATEGY

1. Objectives

The Strategy aims at describing the national context of dementia field in each of the partner countries (Norway, Romania, Italy and Greece) and unfolding the existence and the relevance of the professional figure Peer-Support Worker in Dementia care in these national contexts.

2. Key concepts

This paper focuses on several themes as core aspects of the Peer Support Worker in dementia field, such as:

- Needs in the field of dementia (of people with dementia, informal carers/families, professionals working in the field etc.)
- Role and activity of PSW in dementia field
- Recommendations for public strategies / policies targeting the PSW in dementia field

3. Findings from the 3 Discussion Forums organized in partner countries

In each PIA project partner country, there were organized discussion groups involving informal caregivers (current or former), volunteers, professionals, public authorities and others interested in the topic of dementia and PSW. Their contributions were collected during three face-to-face or online meetings in small groups during which they explored and discussed topics such as the needs, challenges and possible solutions in dealing with informal care for people with dementia, as well as the role that could be played by the figure of the Peer Support Worker (PSW) and the benefits that its introduction could bring.

ITALY

In Italy there were organized three online meetings online on Zoom platform. The participants were told about the PIA project in detail, describing the figure of the PSW and stressing the importance of analysing and understanding it to verify its applicability and usefulness to the field of dementia. Given that this figure does not currently exist in Italy for these pathologies, it was felt that it should be deepened in the field of mental health where, on the other hand, it is a well-established reality, so much so that in 2021 the National Charter of Mental Health Peer Support Experts was promulgated. According to the discussion group participants, the PSW must be an integral part of the dementia care provider/structure both for a kind of legitimacy in the role and guarantee of



professionalism, and to bear the economic burden of this support, which it is believed cannot be shouldered by the family.

ROMANIA

In Romania there were organized three meetings in Bucharest hosted by Association Habilitas and three in Iasi, held by Association AFECT. The sessions of discussions involved representatives of several organizations and associations attentive to the problematic of dementia in our country as well as informal caregivers, either current or former. The objectives were to explore the diverse avenues for accessing services and support for individuals living with dementia and their families. Additionally, they aimed to gather valuable insights from stakeholders to shape the project's future strategy. The focuses of these gatherings were to underscore the specific needs within the dementia field, with a particular emphasis on the potential role and activities of Peer Support Workers (PSWs) in Romania. The discussions also highlighted the current demands within the dementia sphere and the potential advantages that this innovative approach could offer, not only to the healthcare and social-health systems but also to families caring for individuals with dementia. In addition to addressing the immediate needs faced by those dealing with dementia within their families, the discussions revealed challenges and potential solutions as well as recommendations for public strategies aiming to enhance the role of PSWs in dementia care. The Informal Caregivers have proposed several solutions such as: home assistance, legislative reforms, respite care services, empathetic social investigations and improved information dissemination. With regards to the role of PSW there were identified needs and solutions. The involvement of the public authorities in terms of dementia care is paramount, with accent on information campaigns for rights and benefits, training for personal care assistants and informal carers, behavioral management training. Acknowledging the role of PSW as compassionate companionship, practical carer and creator of positive atmosphere it is also important to enhance the collaboration with NGOs working in this area.

All the meetings highlighted the multifaceted needs in the field of dementia care, encompassing the requirements of both health professionals and individuals living with dementia, their caregivers, and the organizations dedicated to this cause. It was also underlined the importance of a collaborative, multidisciplinary approach and accessible procedures, tools, and support for professionals.

GREECE

In Greece Alzheimer Hellas, on behalf of PIA project, organized one online and two onsite discussion forums. The groups constituted of caregivers (previous and current ones), health professionals, psychotherapists specialized in caregiving support, and college students. Each forum had homogenous structure to gain participants' feedback

concerning relevant topics, such as current needs of people living with dementia (PwD), future challenges in dementia care, and the current situation existing in dementia care services.

Additionally, they were encouraged to explore further the role of PSW in dementia care, new ways to boost the motivation of being a PSW, benefits from being a PSW as well as activities for PSW. Furthermore, particular attention was also given to the identification of dementia services, the gaps which a PSW could fill and solutions which could be promoted by health professionals in strong collaboration with PSW.

Given that PSW do not exist in Greek dementia health services yet, future recommendations about their future contribution, figuring out their main characteristics were also discussed. Despite that no representatives from the official authorities were participated in our discussion forums, however, potential public strategies and recommendations from dementia policy makers as well as the Government were also part of our forum's agenda.

Some of the conclusions with regards to the benefits for PSW underlined the fact that their inclusion in dementia care services and be part of the therapeutic team. Cultivating motivation through reflective and empowering techniques could be helpful to enrol those who are interested in helping others based on their valuable experience. Being a PSW can be a paid or unpaid work but the figure of PSW has a crucial role in dementia care.

Conclusions and recommendations

The dedicated work of the partners for elaborating this document (desk research and organization of focus groups in national contexts) highlight the profound challenges faced by informal caregivers, the critical needs of local authorities, and the multifaceted requirements of professionals in the field of dementia care. We can also highlight the significance to train and support PSWs in dementia services, but we are also very willing to provide solutions and ideas on how we can improve the PIA training material and its motivational exercises. We can therefore say that the PIA initiative constitutes a top line achievement which can facilitate the function of dementia services, as well as the quality of life in carers and PwD. The following ideas were underlined:

- the importance of comprehensive support systems;
- legislative reforms;
- collaborative efforts to enhance dementia care;
- the potential of Peer Support Workers and the necessity of standardized training and recognition;



- these insights serve as a powerful call to action for improving dementia care and providing compassion and competence within the healthcare community.

Among the roles and specific duties of Peer Support Workers we can emphasize: compassionate companionship, practical caregiving, establishing daily routines, identifying common interests and hobbies and creating a positive atmosphere.

A specific importance was given to the Peer Support Workers collaborations, as they should closely collaborate with the local authorities and NGOs.

Among the challenges associated with the implementation of Peer Support Workers: there were observed the unpaid role as well as the need for minimal training.

All participants have noticed the necessary skills and knowledge of Peer Support Workers, with respect to the following components: understanding dementia symptoms and progression, medical-psycho-social knowledge, management of effective communication techniques and conflict resolution skills.

As for the role and activities of Peer Support Workers it was noted the importance of community awareness and education, the comprehensive training initiatives together with a clear policy planning, as well-defined policy framework will help ensure that the role of the Peer Support Worker is clearly delineated and supported with all the essential resources.

