The availability, accessibility, and quality of support services for older persons with disabilities in Greece

Contents

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Acronyms

ADL	Activities of Daily Living
AMKA	Social Security Number
EU	European Union
EOPYY	Greek National Health Service Organisation
WHO	World Health Organisation
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning
KAPI	Centers for Open Protection of Older persons
KIFI	Day Care Centers for Older Persons
LTC	Long-Term Care
SUSTAIN	Sustainable Tailored Integrated Care for Older People in Europe
SYD	Supported Living Residences
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

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Introduction

This research explores the care, health, and support needs of older people and, more specifically, older people with disabilities in Greece. It considers similarities and data gathered at European Union and International level. It is based on analysis of relevant literature, data and policy documents and aims to identify the following:

- Care and health challenges of vulnerable persons,
- Approaches to promote care and health and prevent social exclusion for older persons and older persons with disabilities,
- Policy interventions to address care and support challenges to older with disabilities, and
- Other relevant literature, statements and initiatives by health, social and civil society organisations.

A methodologically rigorous approach was taken to conduct a systemic review of literature, which involved using a team of researchers who systematically identified, reviewed, and evaluated literature relevant to the objects of the research.

To do this, a multi-step process was developed and implemented to guide the study and included refining the research questions, setting the focus and parameters of the review, searching, and scoping relevant literature and policy documents, extracting relevant information from scientific literature, policy document and data, focus groups, interviews, on the ground visits in organisations providing support services for older with disabilities, thematic analysis, and synthesis of findings.

This study aims to highlight trends and policies on care provided and developed for older persons with disabilities in Greece. It explores current services in care as well as the challenges met as the result of an international binding framework via the social and human rights approach. It identifies points for further discussion and actions needed mainly at the policy-making level. It also puts forward more specific suggestions, as produced by the carrying out of focus groups, on the ground visits and interviews, about the future of care, either at home or in a residential unit inside the community. It aspires to enrich the policy dialogue between public authorities, stakeholders and civil society and provide an efficient tool for sharpening policies on the study topic.
Although it is acknowledged that all adults with disabilities require additional and specialised support, the focus of this study is on older persons with disabilities above the age of 65. However, old age is not a definite biological stage, as the chronological age denoted as "old age" varies culturally and historically. Furthermore, often people

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who are born with a disability or have acquired it at a younger age are more likely to show signs of premature ageing.

It is also pointed out that care provision can be formal or informal. Formal long-term care is typically provided by a qualified workforce and may be delivered in different settings (residential care, home care, supported living arrangements). Informal care is typically provided by someone from the care receiver's social environment (e.g., a family member, friend, or neighbour), and the provider is not hired as a care professional.

A crucial difficulty about disability policies in Greece is the lack of a census of the population with disabilities in the country, a regular process to record not just the number of persons with disabilities, but also their distribution in the regions of the country, their age and gender, income, and level as well as other essential features. Thus, a coherent policy to get deep understanding of their real needs could be developed, enabling society and State to address relative policies and design their implementation based on reliable data. So, inevitably, the effort of having a quantitative assessment of the research objective, necessarily, will be based on indirect evidence that arises from other studies and research that might not focus on disability per se, but on social and health care, older people in general, etc.

This analysis identifies gaps and confirms the need for coordinated action for older persons with disabilities as there is a legal obligation, a strong request from all involvement parties, and State's will. The vulnerability status remains a key characteristic whereby it is affected by several societal and environmental factors and the availability and distribution of support and care resources. Gender also is a factor that affects the level of access to care, health, support services for older persons with disabilities.

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Chapter 1: Older persons with Disabilities – Vulnerability

1.1 Definitions

There is no single definition of disability[1]. Defining disability is complicated as it is 'complex, dynamic, multidimensional and contested'[2] . Disability is part of being human. Everybody is likely to experience difficulties in functioning at some point in their lives, particularly when growing older. How much disability a person experiences in daily life varies greatly and is dependent upon how their impairment or health condition interacts with barriers in society. Disability is a global public health issue because it affects an estimated fifteen per cent of the world's population with increasing prevalence due to a rise in chronic health conditions and populations' ageing[3].

Article 1 of the United Nations Convention for the Rights of Persons with Disabilities (UNCRPD) sets out its purpose, which is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." The Convention is a human rights treaty designed to protect the human rights and inherent dignity of persons with disabilities.

The Convention protects all persons with disabilities, who are defined in Article 1 as including "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." This broad definition adopts what is known as the social model of disability. It recognises that disability is an evolving concept and that persons with disabilities are often prevented from exercising their human rights and fundamental freedoms by barriers of attitude and environment that have been placed in their way. In other words, the Convention seeks to alter social attitudes by ensuring that governments, individuals, and organisations recognise that all persons have the same human rights and fundamental freedoms.

Disability is a human rights issue with persons with disabilities being subject to multiple violations of their rights, including acts of violence, abuse, prejudice, and disrespect because of their disability, which intersects with other forms of discrimination based on age and gender, among other factors. Persons with disabilities also face barriers, stigmatisation, and discrimination when accessing health and health-related services and strategies.

[1] Mitra, S. (2006). The capability approach and disability. *Journal of Disability Policy Studies*, *16*(4), 236-247
[2] WHO & The World Bank. (2011). *World report on disability*
[3] WHO, Report on ageing and health, 2015?

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Disability is a development priority because of its higher prevalence in lower-income countries and because disability and poverty reinforce and perpetuate one another[4].

Persons with disabilities are a diverse group of people with a wide range of needs. There are many types of disabilities, including physical, sensorial, cognitive, intellectual, and psychosocial, that can affect a person's vision, movement, thinking, remembering, learning, communicating, hearing, mental health, and social relationships. Two people with the same type of disability can be affected in very different ways.

1.2 Defining older persons with disabilities

Older persons are conventionally defined as people over the age of 65, so most of the census statistics classify people over the age of 60-65 as the older persons population. The age limit of 65 is more related to retirement and less to the deterioration of normal functions. This conventional categorisation results in people over the age of 65 being included in studies with younger people of very different physical condition, eventually forming a heterogeneous group with large variations in physical and mental health. The terms "older persons" and "old age" remain vague and, although there is no strictly defined biological limit, the 65th year is usually considered the threshold for the transition to third age.[5]

Apart the age dimension, the most frequent approach is to define the older persons with disabilities as those who require assistance with basic Activities of Daily Living, commonly referred to as ADLs. ADL has become an accepted way to define and measure the long-term care population because disability in activities of daily living is a direct indicator of the need for care.[6]

In addition to functioning in core ADLs[7], researchers also sometimes include measures of functioning in what is called Instrumental Activities of Daily Living, or IADLs. IADLs include such activities as the ability to prepare meals, take medications properly, go grocery shopping, do housework, and manage money. Many older individuals do

[4] World Health Organization, International Classification of Functioning, Disability and Health (ICF) external icon. Geneva: 2001, WHO

[5] Haniotis, F. I. (1999). Manual of geriatrics. Athens: Litsa Medical Publications

[6] Katz, S., Ford, A., Moskowitz, R., Jackson, B., and Jaffe, M. "Studies in the Illness in the Aged: The Index of ADL: A Standardized Measure of Biological and Psychosocial Function." Journal of the American Medical Association Vol. 185(12):914-919, 1963.

[7] These core ADLs are: (1) bathing; (2) dressing; (3) using the toilet; (4) transferring from bed to chair, and (5) feeding oneself.

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not require assistance in core ADLs, but still, have impairments that prevent them from performing these IADL activities without occasional or constant help from other persons.

Another feature that is often used to measure disability is cognitive functioning. Many older individuals, including persons with Alzheimer's disease, are often physically capable of performing ADL and/or IADL activities but still are unable to perform them independently because they have cognitive impairments. Impairments in cognitive functioning often led to greater assistance needs, up to 24-hour supervision, so they do not harm themselves or others (e.g. by forgetting to turn a stove).

A general thought is that older people are counted as being disabled if they cannot perform a certain activity on their own. The most common approach is to define someone as disabled older person if he or she requires the help of another person to perform the activity with either active or stand-by help. Thus, older persons who rely on assistive devices only are generally not counted in estimates of the population in need of long-term care (LTC), because they do not require the assistance of another person. Finally, definitions of functional impairment also include a dimension of chronicity to exclude individuals who may have only temporary limitations in ADLs due to acute conditions (e.g. a recent operation, the bout with the flu, etc.).

According to the latest available data concerning people in need of LTC in Greece, the share of population aged 65 and over defined as having at least one severe difficulty in ADLs and/or IADLs was 29.1 % in 2019. In addition, the share of potential dependents in the total population in Greece was 9.7 % (or 1.034 thousand people) in 2019, which is above the EU-27 average (i.e. 7 % in 2019).

Projections indicate that the share of potentially dependent people in the total population is estimated to reach 10.6 % (or 1.090 thousand people) by 2030 and 12.6 % (or 1.195 thousand people) by 2050. Looking at all this, it becomes evident that Greece is facing significant demographic changes, which are expected to trigger an ever-increasing demand for LTC services. What is of rising concern, however, is that this challenge - adapting service provision to cover the ever-increasing demand - is barely being addressed in Greece, considering that LTC has never been given due attention by either governments or policymakers and is a rather neglected policy area.

Research in Europe suggests that health expectancies differ significantly among countries. A pooled analysis by WHO in 2014 of extensive studies conducted in high-income countries indicated that although the prevalence of severe disability (that is, a disability that requires help from another person to carry out basic activities such as

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eating and washing) may be declining slightly, no significant change in less severe disability has been observed during the past 30 years[8]. Thus, the current evidence from high-income countries is confusing but suggests there may be a slight reduction in some forms of disability at a given age, although this is unlikely to be keeping up with the added years people are living.

This lack of clarity is sharpened by several significant research limitations. First, disability is generally accepted to be a state determined by both the underlying characteristics of individuals (that is, intrinsic capacity) and the environments they live in[9]. Unless researchers consider changes at both these levels, they will be unable to distinguish between them. According to the literature, functional disability in older persons may be associated with several individual factors, such as socioeconomic variables, the presence of diseases, and psychosocial factors. It is noteworthy that detecting these factors that have an influence on the functional ability of older people is essential to understand and implement prevention and intervention measures based on the observation of a specific population[10].

Therefore, preserving functional ability should be a priority aspect in terms of older persons health care because, in addition to compromising the autonomy[11] of older people, impaired functional ability brings consequences to the family, community, health system, and the older persons themselves, causing greater vulnerability and dependence in old age, having an impact on their quality of life, and increasing their chances of geriatric syndromes.

Programmes such as SUSTAIN (Sustainable Tailored Integrated Care for Older People in Europe) consist of a range of international experts working in the field of care for older people, collaborating to improve integrated care initiatives within several Member States. The project began in 2015 and is funded under the European Union Horizon 2020 programme for research and innovation. Starting from the assumption that care for older people is often poorly coordinated, and this prevents older people from receiving care that adequately meets their

[8] Chatterji S, Byles J, Cutler D, Seeman T, Verdes E. Health, functioning, and disability in older adults–present status and future implications. Lancet. 2015 Feb 7;385(9967):563–75. doi: http://dx.doi.org/10.1016/S0140-6736(14)61462-8 PMID: 25468158

[9] International classification of functioning, disability and health. Geneva: World Health Organization, 2001

[10] Functional disability and associated factors in urban elderly: a population-based study,2016

[11] Hung WW, Ross JS, Boockvar KS, Siu AL. Recent trends in chronic disease, impairment and disability among older adults in the United States. BMC Geriatr 2011;11(47):1-12.

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complex health needs, the programme supports existing initiatives by engaging a wide range of stakeholders to bring knowledge and experience to models of integrated care and ensures that learning and practices are applicable and adaptable to other health systems and Member States (SUSTAIN, 2016).

1.3 Differences within the Disabled Older Population

Older persons with disabilities are not a homogeneous group. They have important individual differences that those who design programs and services should be aware of if they want to develop interventions that will meet real needs.

Thus, it is generally useful to define three large groups[12]:

1. There are a substantial number of older people with relatively mild impairments who do not require the active help of other people daily. They can generally manage their daily activities on their own (i.e. they are not disabled in any of the core ADLs) perhaps with the help of mechanical devices, although they may require the occasional assistance of other people to help with IADLs such as shopping, cleaning, doing the laundry, yard work, preparing medications, using the telephone and so on. Many have intellectual mild impairments, but do not require continuous supervision. This group relies almost exclusively on family members and other informal caregivers for assistance.
2. There is another large group of people with multiple health problems and severe limitations in intellectual and/or physical functioning who require very intensive (often 24 hour) support. They are generally impaired in three or more ADLs. Many are in chronic care units, and others live in the community with the assistance mainly of family carers. Many people in this second group have chronic severe impairments over an extended period and require intensive levels of care for months or years. An individual in the advanced stages of Alzheimer's disease is an example of a person in this third sub-group.
3. In between these two extremes, there are older persons with moderate impairments. They are functionally impaired in one or two ADLs or have mild cognitive impairments. They generally live in the community, either in their own homes, in the homes of close relatives, or supportive housing

[12] Brian O. Burwell and Beth Jackson “The Disabled Elderly and Their Use of Long-Term Care” SysteMetrics

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arrangement. These individuals are heavily dependent on informal care if family members are available to provide care, sometimes supplemented by formal services.

A separate subgroup in the older persons population with disabilities consisted of those who did not develop their disability due to age but were diagnosed as disabled either by birth or younger age. This category differs mainly in the fact that it was part of the formal or informal support system before they became older. People with disabilities age like everyone else, and as levels of care improve, more and more people with disabilities reach older ages. For these people, the difficulty lies mainly in the inability of support frameworks to adapt to meet their changing needs. They are often forced at an older age to leave the services they have been in for many years and join new ones such as nursing homes that mainly accommodate older persons who were not disabled when they were younger. These services often lack the training, the know-how and the resources to adequately respond to the needs of older persons who have been disabled all their lives.

1.4 Disability and Classification

The World Health Organization (WHO) published the International Classification of Functioning, Disability and Health (ICF) in 2001. The ICF provides a standard language for classifying body function and structure, activity, participation levels, and conditions in the world around us that influence health. This description helps to assess the health, functioning, activities, and factors in the environment that either help or create barriers for people to fully participate in society.

According to the ICF:

- **Activity** is the execution of a task or action by an individual.
- **Participation** is a person's involvement in a life situation.

The term 'disability' in the new ICF is thus defined as follows:

“an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that ' 'individual's contextual factors (environmental and personal factors)". (WHO 2001:213)

Central to this definition of disability is the relationship between the individual (with a health condition) and environmental factors (physical, social, and attitudinal). It is the interaction of the person's health characteristics and their contextual factors (environment, personal) that produces a disability. If a person with a given health

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condition lives in an environment characterised by barriers at every level their performance will be restricted; but if a person lives in a facilitating environment this will serve to increase their performance.

Also, ICF covers Contextual Factors. At the conceptual level, these are divided into: Environmental factors and Personal factors. Environmental factors comprise the physical, social, and attitudinal environment in which people live, and which are external to the individual. At individual level, they include the physical features of a person's environment, the available communication devices, and the support networks (family, friends etc.) they have on a day-to-day basis.

Personal factors are features of the individual that are not determined by their health condition– including for example, gender, race, age, lifestyle, social background, education, occupation, and psychological characteristics. Such personal factors are not actually coded in the ICF framework itself but are included in the conceptual model which underpins it[13].

1.5 Demographic Data

1.5.1 Comparative data for older persons at Greek and European level

Greece is conducting a Population and Housing Census in 2021 as part of the wider European Union census, with results available in 2024. The last census in Greece was conducted in 2011 and showed a total population of 10.81 million (51% female, 49% male).

Life expectancy at birth in Greece is 84 years for women, and 78.9 for men. The proportion of the population aged 65 and older has risen to 20.68%, while the proportion of those younger than 14 has declined slightly to below 14%. An ageing population increases demands on health care and pension resources and affect public funding for older persons. Marriage rates have slightly fallen whilst divorce rates have seen an increase, contributing to a generalised situation of smaller households than in previous years. The demographic situation in Greece seems to follow the European trends as EU surveys show that the working-age population (between 15 and 65) is projected to fall from 333 million to 292 million in 2070.

[13] International classification of functioning, disability and health. Geneva: World Health Organization; 2001.

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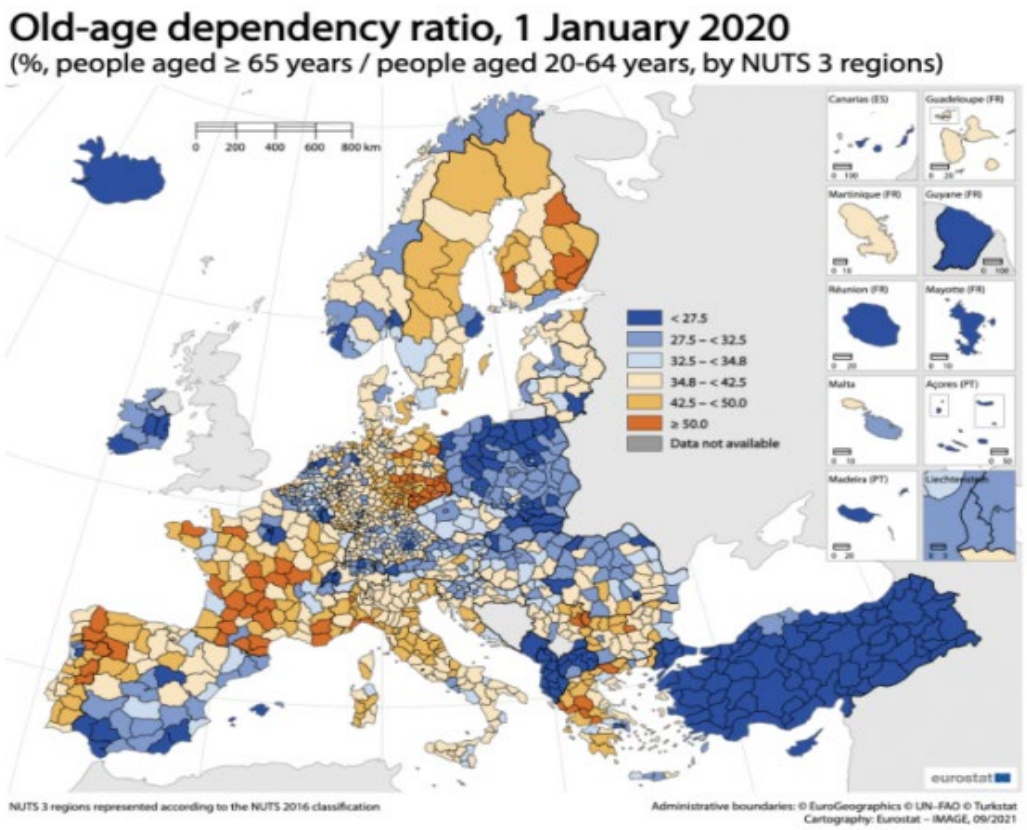
Also, although Greece's population has decreased over the period 2009-2019 and is expected to decrease further[14], Greece has one of the highest population ageing rates in the EU. Eurostat data reveals that in Greece the share of people aged 65 and over has an increasing trend, from 18.7 % (or 2.1 million people) in 2008 to 22.0 % (or 2.4 million people) in 2019, remaining one of the highest among the EU-27 Member States[15].



Apart from Greece, Spain, France, Italy, Portugal, Finland, and Germany have significant ageing population. This is predominant in rural, mountainous, or relatively remote areas, which young people have left in search of employment.

[14] The total population in Greece was estimated at 10.7 million people in 2019, showing a decrease of 3.6 % compared to the population of 2008 (i.e. 11.1 million), while it is projected to be 10.3 million people by 2030 and 9.5 million people by 2050.

[15] EU-27 refers to the current 27 Member States of the European Union

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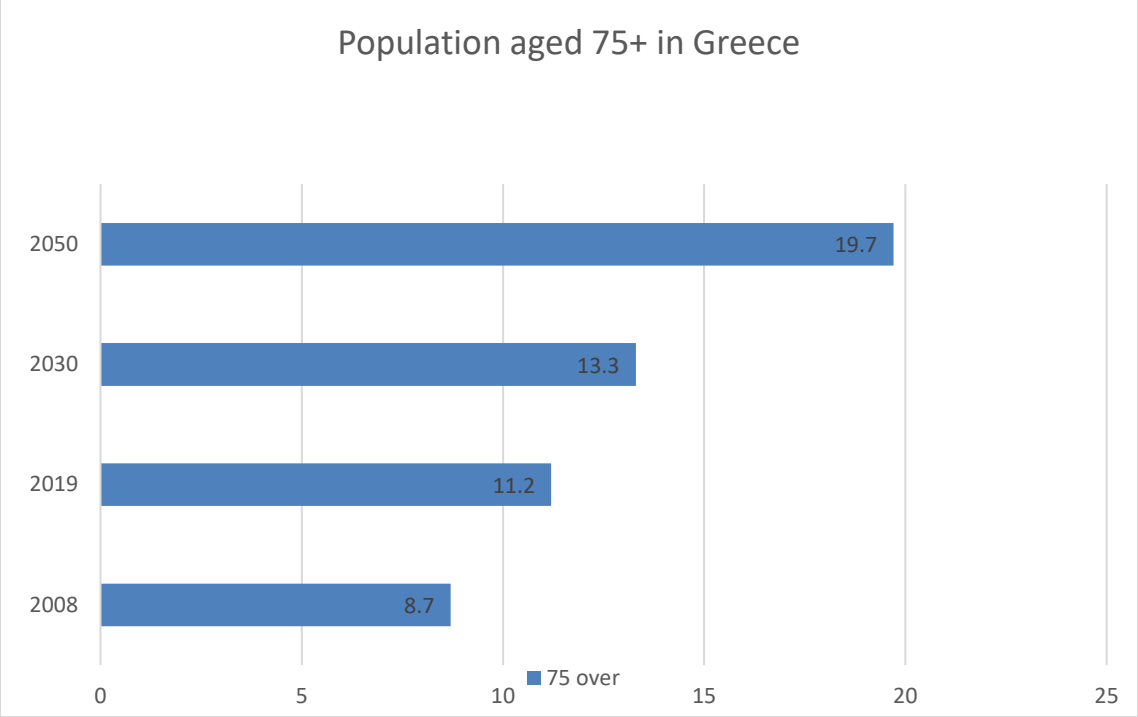
This trend is expected to increase in all European regions, with the older persons dependency rate reaching 56.7% in the EU on 1 January 2050, meaning there will be less than two people of working age for every person over 65.

This is also the case with the share of people aged 75 and over (i.e. from 8.7 % in 2008, it increased to 11.2 % in 2019). The challenge that this demographic development poses to LTC becomes even more pressing when one considers that the proportion of people aged 65 and over in the total population in Greece is projected to reach 25.8 % (or 2.7 million people) by 2030, and 33.8 % (or 3.2 million people) by 2050. Similarly, the share of people aged 75 and over in the total population is projected to reach 13.3 % by 2030 and 19.7 % by 2050.



Source: Ageing Europe, 2109 Edition

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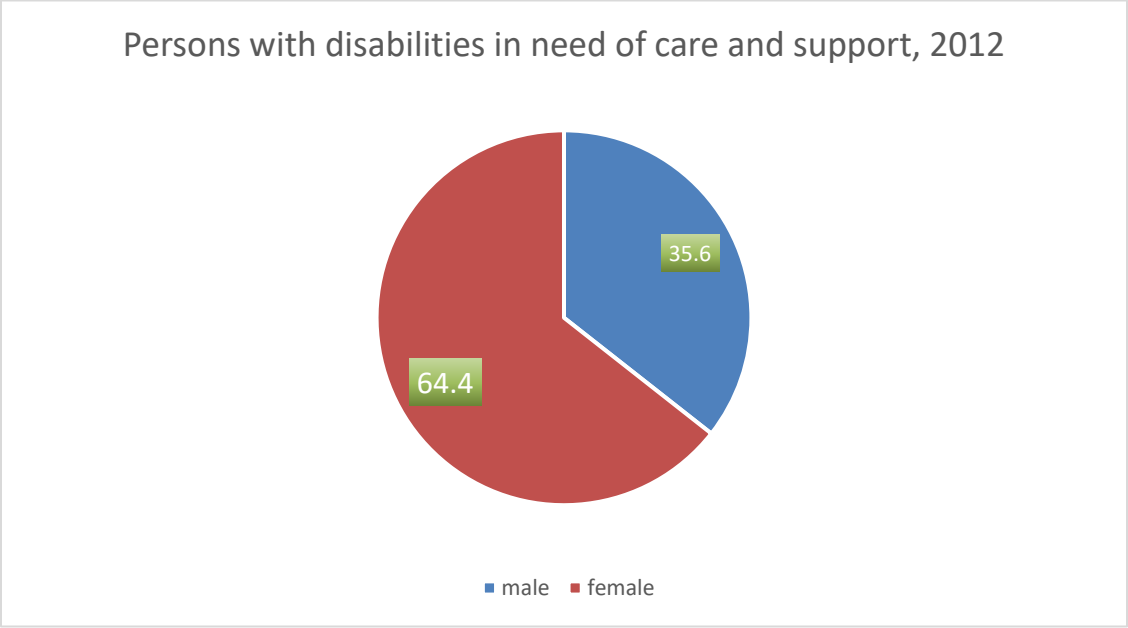
1.5.3 Comparative data for persons with disabilities at Greek and European level

The overall percentage of persons with disabilities in the EU amounts to 17.6% for the population above 15 years old. The variation is significant in some cases (12% in Malta and almost 25% in Hungary), and this is linked possibly with factors such as the aging population in each individual country. The percentage of disability in Greece is presented at about the European average, while the number of the disabled (1,686.6 thousand people) seems to be practically at the level of the 2002 survey[16]. In addition, if the above data also included the share of the total population up to 15 years, the rate of disability in societies would be lower. In any case, the great weight and importance of the issue of disability is identified in all modern societies.

Of the total number of disabled people in Greece, again according to Eurostat data of 2012, about 680.000 (i.e. 40.3% of the disabled in the country) needs care and support. Of those, 35,6% were men, and 64,4% were women[17].



EU-27 refers to the current 27 Member States of the European Union

[16] Mobility disabilitites and social policy at Greece: an introductory approach, National Institute of labour and human resources, 2020
[17] Hellenic Statistical Authority, Research for Persons with Medical Health or a Disability (ad hoc 2002)

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One of the most crucial difficulties on disability policies in Greece is the lack of a comprehensive census of the population with disabilities in the country, a regular process to record not just the number of persons with disabilities, but also their distribution in the regions of the country, their age and gender, income, and level as well as other essential features. Thus, a coherent policy of deep understanding of their real needs should be developed, enabling society and State to address relative policies and design their implementation based on reliable data.

As it results from the above analysis, there are some data that generally concern the populations of older persons and people with disabilities in Greece and give us a rough picture of the situation. However, there are no studies that specifically focus on the target population of the present study, i.e. older persons with disabilities. So, inevitably, the effort of having a quantitative assessment of the research objective, necessarily, will be based on indirect evidence that arises from other studies and research that might not focus on disability per se, but on social and health care, older people in general, etc.

Regarding the care provided to people with psychosocial disabilities, it needs to be mentioned that there are 510 community residential structures for these persons. These provide accommodation, care, and protection services (sheltered boarding houses and apartments, sheltered workshops, etc.) to about 4.100 beneficiaries. They are operated by public and non-profit organisations, and they are financed by the State and Greek National Health Service Organisation (EOPYY). In these services, there are about 2.100 beds in sheltered boarding houses (or hostels) for older people with psychosocial health problems that can be counted as LTC beds. In addition, there are 338 beds in public psychiatric hospitals that can be used for the LTC of chronically mentally - psychosocial ill persons[18].

1.6 Social Facts

Greece achieved notable progress in improving the well-being of its population in the period following the Second World War. However, socioeconomic gains were undermined by the financial crisis of 2008, which was followed by a decade of austerity.

[18] Data obtained from the Ministry of Health

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These years of financial recession and related austerity measures have played their part, and Greece has one of the lowest levels of public expenditures on the social sector among the EU Member States. This has an impact on the implementation of existing policies targeting poverty reduction and social inclusion, particularly affecting marginalised groups. Nationwide inequalities in life expectancy are related to socioeconomic status, notably among men, where men with a higher level of education can expect to live six years more than those with the lowest level of education. These figures are primarily the result of poorer lifestyle choices among men with a lower level of education and include factors such as smoking or obesity. Women also face poorer health outcomes based on their socioeconomic status, but to a lesser extent (with a 2.4-year difference). The higher prevalence of risk factors among socially disadvantaged groups contributes to inequalities in health and life expectancy. And indeed, these patterns are followed by older persons with disabilities.
Emergency cases for all vulnerable groups are admitted to the hospitals without preconditions. Still, free access to regular public healthcare services is provided when individuals possess (or acquire, if they do not already have one) a Social Security Number (AMKA). While those who are insured have access to private providers contracted with EOPYY on a cost-sharing basis and public health care, uninsured persons are not entitled to such private cost-shared access to healthcare.

The Greek government launched a few programmes to reallocate resources and distribute financial assistance, including through a Guaranteed Minimum Income since 2017[19], which is complemented by a set of services. These efforts respond to the UN Sustainable Development Goal 1 that calls for an end to poverty in all its manifestations by 2030 and specifically to the target 1.3 on implementing nationally appropriate social protection systems. This set of policy initiatives is integrated into the framework of the National Priority for "Addressing poverty and social exclusion and providing universal access to quality health care services" as part of the eight SDGs National Priorities outlined in the Voluntary National Review on the Implementation of the 2030 Agenda for Sustainable Development.

In 2017, Greece invested €1,623 per capita in healthcare – more than one-third less than the European Union average. The value for money, adequacy, and equitability of spending, especially through an elderly disabled lens, are difficult to assess, as there has been limited budget performance evaluation and parliamentary and citizens' engagement in the budget process is low.

[19] Ministry of Labour and Social Affairs, 2017

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As about social expenditure at the European level, Greece has experienced a significant reduction in social protection spending per capita, especially after 2010 and the fiscal years' adjustments that followed. Specifically for expenditure related to disability benefits, Greece spends around 1% of GDP, in contrast to the European Union average of around 2%. Total per capita social protection expenditure related to disability in the EU28 has increased by 15.6% in the period 2010-2017, while for the same period in Greece there has been a decrease of 46.9%.

Regarding the distribution of total costs among the various functions, it is observed that over time the benefits for older persons and persons with chronic illness occupy the lion's share (53.9% for 2018, compared to 4.02% for disability). At the same time, an interesting element is the fact that most of the social protection benefits in Greece are given as cash benefits (92.4% for 2018), while other types of benefits are significantly limited overall (7.6% for 2018), a picture that is not in line with the most of EU countries.

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Chapter 2: International legal frameworks

2.1. The United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted in 2006 and entered into force in 2008. The Convention focuses on empowering persons with disabilities as autonomous individuals capable of making informed decisions for themselves rather than as 'objects' of charity or medical care. The EU adopted the UNCRPD in 2009 and it entered into force in the EU in 2011. Greece ratified both the Convention and its Protocol with Law 4074/2012 on the "Ratification of the UN Convention on the Rights of Persons with Disabilities and the Optional Protocol to the Convention on the Rights of Persons with Disabilities" (OGG 88 A'), which came into force in June 2012.

In accordance with Article 19 of the UNCRPD, persons with disabilities have an equal right to live in the community, with choices equal to others; and governments must take effective and appropriate measures to facilitate their full enjoyment of this right, and their full inclusion and participation in the community. Services provided for long-term care must be delivered according to the UNCRPD, fully respecting the rights and fundamental freedoms of people with disabilities.

Article 25 of the UNCRPD focuses on the health of persons with disability. It sets out the right to the highest standards of healthcare for those with a disability. It highlights:

- the requirement that persons with disabilities receive the same range of affordable or free healthcare as the rest of the population and with all health services they require because of their disabilities;
- that these health services should be as close as possible to where people are living (including those that live in rural areas);
- that health professionals provide the same quality of care for those with disabilities as to those without;
- the prohibition to discriminate persons with disabilities in terms of health and life insurance;
- the prohibition to deny any health services, food, or fluid on the grounds of disability.

In addition, article 26 of the UNCRPD deals with the aspect of habilitation/rehabilitation for persons with disabilities. Habilitation and rehabilitation include a range of measures – physical, vocational, educational, training-related and others – necessary to empower people with disabilities to maximise independence and the ability to participate in society, not simply to achieve physical or mental health. For this reason, the right to health

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and the right to habilitation/rehabilitation are addressed separately. It shows how important is inclusion via a range of support and care developing services.

2.2 United Nations Principles for Older Persons

The United Nations Principles for Older Persons were adopted by the UN General Assembly (Resolution 46/91) on 16 December 1991. Governments were encouraged to incorporate them into their national programmes whenever possible. There are 18 principles, which can be grouped under five themes: independence, participation, care, self-fulfilment, and dignity. It highlights that older persons should benefit from family and community care and protection in accordance with each society's system of cultural values, should have access to social and legal services to enhance their autonomy, protection, and care, should be able to utilise appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment. All older people should be able to live in dignity and security and be free of exploitation and physical or mental abuse as well should be treated regardless of age, gender, racial or ethnic background, disability, or other status.

2.3 European Pillar of Social Rights

The European Pillar of Social Rights expresses principles and rights essential for fair and well-functioning labour markets and welfare systems in 21st century Europe. It reaffirms some of the rights already present in the Union acquis. It adds new principles which address the challenges arising from societal, technological, and economic developments. For them to be legally enforceable, the principles and rights first require dedicated measures or legislation to be adopted at the appropriate level. The European Pillar of Social Rights specifically recognises the right of people with disabilities to inclusion (Principle 17): People with disabilities have the right to support that ensures living in dignity, services that enable them to participate in society, and a work environment adapted to their needs, also relevant to persons with disabilities is Principle 14 on the right to affordable long-term care services of good quality, in particular homecare and community-based services (Principle 18).

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Chapter 3: Legal framework, support services, and programmes for older persons with disabilities in Greece

3.1 Greek care and support framework

In Greece, the framework (see Annex I) for the provision of care and support services to older persons is based on a mixed system of services comprising formal (provided by public and private entities) and informal care, with primary responsibility for the financial and practical support of dependents resting firmly on the family. Since the beginning of the 2000s, there has been a significant increase in LTC services that provide social support and care for older persons with disabilities at home and in the community.

These include a) day care centres for persons with disabilities' 'KDIF', day care centres for older persons' 'KIFI' and centres for open protection of older persons' 'KAPI', b) services provided to older persons with or without disabilities at home 'Help at 'Home' programme and c) supported living residences-(SYD) for persons with disabilities, mainly with intellectual or developmental disabilities.

Apart from these, LTC is provided to older persons with disabilities through a) private care units and b) public social care units and chronic illness nursing homes. These two types are linked with residential/institutional care. The long-term care and support units offered to older persons with disabilities lacks an efficient regulatory framework as the system continues to be highly fragmented and unstructured. As a result, the licensing and the provision of these services are based on several frames of reference. More specifically, the regional authorities are responsible for the licencing (establishment and operation) and monitoring processes of the institutional/residential care services, while local authorities undertake to operate the services that provide community-based support.

3.2 Day Care Centers for older persons (KIFI)

The "Day Care Centers for older persons" (KIFI) are units that provide day care to older persons who are not entirely self-sufficient (due to mobility difficulties, dementia, or mild mental disorders) and whose caregiver environment faces serious social and economic problems or health problems and is unable to support them. They operate in specially designed areas daily and can accommodate older persons for a short period of time by providing services (daily hygiene and nursing), entertainment and creative activities. Since their establishment, they have been funded mainly through EU resources. According to current regulations, they are co-funded by

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the European Social Fund and national/local budgets. KIFI cooperate with local social and health services as well as with the welfare directorates of the regional units (ex-prefectures) of the country

What is missing from this programme are the mobile rehabilitation units and mobile diagnostic units with an interdisciplinary team as well the establishment of home nursing programs. According to the latest available data[20], there are 68 KIFI in operation, accommodating about 1500 older people with a staff of about 300 people.

3.3 Centers for Open Protection of older persons (KAPI)

The "Centers for Open Protection of older persons" (KAPI) were founded in Athens in 1979, and since then, over 700 have been in Nationwide operation. These centres were originally planned to provide a wide range of services to older persons: leisure and organised excursions and visits to museums and archeological sites, basic medical and nursing care, social support, physiotherapy and occupational therapy, home care for older people living alone and have no other support, training programs etc. Their basic philosophy is to defend the social rights of older persons, with particular emphasis on community living in the family environment, the neighbourhood, and the avoidance of any form of institutionalisation.

Lack of resources, a growing number of users (exceeding capacity) and lack of staff has led to the partial operation of these services and an emphasis on leisure activities, nursing, and social support. However, KAPI are very popular care services, and their beneficiaries appreciate them a lot.

3.4 Help at Home Programme

The "Help at Home" programme is aimed at seniors who are not fully self-supported and people with mobility impairments and special problems, with priority given to those who live alone, do not have full family care or whose income does not allow them to provide the services needed to improve their quality of life. The purpose of the Program is to improve the quality of life of older persons as well as persons with disabilities, to assist autonomous and dignified living, to support the family environment of the beneficiaries and finally to promote their social inclusion.

The programme ensures close cooperation with the competent local authorities, the medical staff, the hospital and the other health and welfare services.

[20] EETAA, Local Authorities in Numbers, Special Edition of the Hellenic Agency for Local Development and Local Government (EETAA), Athens, 2017.

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Up until 2015, it received financial support from the European Social Fund; since then, the programme has been financed by national resources alone, and its funding has been secured until September 2020 (Law 4635/2019, article 229). At present, there are 859 'Help at Home' schemes in operation, run by 277 agencies (municipalities, municipal enterprises, non-profit organisations, etc.) and providing services to about 70,600 beneficiaries[21]. The schemes provide nursing care, social care services and domestic assistance to older people (aged 78 and over) and people with disabilities (irrespective of age) who live alone and face severe limitations (mobility problems, etc.) in their everyday lives, and who fulfil specific – rather strict – income criteria[22]. About 3000 people (social workers, nurses, physiotherapists, and home helpers) are employed in these schemes, most of them on a fixed term-contract basis.

The "Help at Home" programme in Greece is a successful social support program, positively evaluated by the local communities. However, there are substantial problems, the most important of which concerns the uncertainty about the program's future funding, and therefore its viability. Other issues relate to the program's technological infrastructure, which is in many cases non-existent, and to the inadequate training and further education for the program's personnel[23]. The "Help at Home" Programme sets as its primary goal "to meet the basic needs for social care and decent living for older persons and persons with temporary or permanent health problems or disability".

The programmes operate with fairly very good results in most cases. In studies of this or other similar programmes (KAPI) the degree of satisfaction showed extremely high levels and ranges over 80% (Alexiou and Flamou, 2007; Pergamali, 2006; Chalkoutsaki, 2006; Daniilidou et al., 2003). These data may not be completely accurate, mainly because older persons are often prone to errors of response (Bauld et al., 2000; Geron, 2000). Nonetheless, the satisfaction rates are indeed high, which fully justifies the adoption of such programmes and stresses the need for their further widening and expansion. Moreover, their operation has employed a significant number of people, thus contributing to solving the problem of unemployment at the local level (ANKA, 2006).

[21] EETAA, EETAA's Newsletter August-October 2019. https://www.eetaa.gr/newsletter/teyxos10.pdf.
[22] It should be noted that the income criteria vary among the 'Help at Home' schemes. In most cases the beneficiary's annual income cannot exceed EUR 7500 - EUR 8000.
[23] K. Sotiriadou, L. Antonopoulou "PEST and SWOT Analyses of the "Home Care" Program in Greece", Hellenic Journal of Nursing Science, Volume 02 • Issue 02

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The services provided to older persons facilitate the assurance of a dignified and healthy living in their own homes. At the same time, the beneficiaries' families are alleviated and disengaged by an important load of care. Many cases would end up in the patient's institutionalisation, were not for the program's provision of care for chronic illnesses. Also, relationships with other services can be expanded and strengthened to allow broader cooperation, exchange of good practices, joint actions, and initiatives.

The “Help at Home”, a worth developing programme, focuses on enhancing social inclusion with positive overall feedback from its beneficiaries. Its main weaknesses include staff shortages and a lack of efficient organisation and management. It's the case that the main components of this program have been developed to fit the care needs of non-disabled persons, and as a result, the staff is not sufficiently trained to cover the specialised care and support needs of older persons with disabilities. In addition, these difficulties reflect negatively in ensuring continuity of care provision to older persons with disabilities and persons with intellectual disabilities.

Also, other weak features of this programme are the non-operation on weekends and the lack of telecare / telehealth services for long distance support, for the older persons in urban, rural, and insular areas. It cannot implement innovative monitoring programs through wearables, telecare, GPS locators to lengthen safe self-living.

3.5 Older persons Care Units (MFH)

Care Units for older persons are run by for profit and non-profit organisations, the majority of which are based in urban areas. These units are financed from the state budget and from fees contributed by the insurance funds for their beneficiaries, with the rest of the funds depending on the legal status of each unit. In 1995, the institutions for older persons of various kinds were renamed "Older persons Care Units" (Law 2345/1995) and operate as legal entities under private law. The role of the Greek Orthodox Church is important, with 80 units founded and run by ecclesiastical organisations. They accommodate people with low income. The for-profit residential homes are privately paid for by the person in care and their families, while the non-profit care homes are partly subsidised by the State and partly funded by donations (and per diem fees paid by EOPYY for those

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entitled to social insurance). The Ministry of Labour and Social Affairs (2021) estimates that there are 310 Elderly Care Units in operation accommodating 13,100 older persons[24].

3.6 Supported Living Residences (SYD)

According to the most recent data from the Ministry of Labour and Social Affairs, today in Greece operate 103 SYD with 502 residents. Supported Living Residents (SYD) are the homes available for the permanent living - residence of persons with disabilities with properly organised support and relative services. Bodies for the establishment and operation of SYD can be either public law entities or private law non-for-profit or for-profit organisations according to the 13107/283/08-04-2019 Joint Ministerial Decision (OGG:74 'B').

Supported Living serves the primary right to independent living of every individual and at the same time aims at the development and maintenance of the maximum degree of skills and abilities of the residents. In addition, Supported Living also aims to avoid the marginalisation or institutionalisation of persons with disabilities, when the immediate family environment is unable for any reason to support their livelihood. Therefore, Supported Living addresses the issue of living-housing of persons with disabilities, mainly with intellectual with a long-term or lifelong perspective. The operating purposes of the SYD are adapted to the special needs and characteristics of their beneficiaries.

SYD accommodate persons with disabilities above 18 years old and they're counted as a very important programme supporting even older persons with disabilities. They're ensuring the dignity of the residents as their operation is linked with the fundamental principle of inclusive living in the community. Ageing is a crucial factor for persons with intellectual disabilities living at SYD. As these persons get older, they demand additional care and support which is also linked with concomitant disorders. Although there are no law restrictions to the type and the quality of the support that should be provided to the residents with additional needs, there is a necessity for the development of a new regulatory framework. This framework will adopt the demand for sufficient support inside the SYD, covering the individualised needs based on care provided to all residents regardless their age or medical health status. In Greece operate 103 SYD with 502 residents[25].

[24] Ministry of Labour and Social Affairs, Data 2021

[25] Data, Ministry of Labour and Social Affairs

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3.7 Day Care Centers (KDIF)

The Day Care Centers (KDIF) are a type of Rehabilitation Centers, and they are operating under the Ministerial decision No. 4633/29-09-1993 (OGG 'B' 789). Public and private profit and non-profit organisations have developed and operate these centres throughout the country. Their main goals are to provide care services as well as vocational training to their beneficiaries. More specifically, they provide individual care and therapies, employment training, entertainment, and psychological support to develop the skills and abilities of persons with disabilities. These services allow them to get the necessary skills to live independently and actively. In Greece operate 94 KDIF, with 2.800 employees, offering services to 4.800 beneficiaries[26]. Although there is no age limitation, usually, persons with disabilities over 55 are driven to exit, looking for an alternative support provision due to the inability of the service provider to offer efficient services. That is not always the rule but is happening very often, because of the inability of the organisation to adapt its services to cover the support and rehabilitation needs for these persons efficiently. Therefore, persons with disabilities that get older often are driven to other programmes such as “KAPI” which are offering very limited services for older persons with intellectual or other kinds of disabilities. This has a significant impact at the psychosocial level of the user and increases his/her dependency.

3.8 Health & Care Challenges

In Greece, the services and structures of long-term care and permanent living of the older persons and older with disabilities are provided by public bodies, by non-profit Organisations (Church, charities, etc.) and by non-profit Organisations (Older persons Care Units). However, Greek society is family-centred and very often persons with disabilities and older persons are primarily cared for at home by family members. The Older persons Care Units in our country cover a small percentage of the current housing needs.

The challenges facing the care system for older persons are well-known including an ageing population with increased demand for services, confusing and fragmented service delivery, waiting lists, substandard care, a lack of transparency about the quality of services, an under-resourced and under-skilled workforce. Too often, the older persons care system seems deaf to older peoples' needs and preferences. Each of these and other problems needs to be addressed.

[26] Data 2021, Ministry of Labour and Social Affairs

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The demographic changes leading to increasing demand for elderly care over the coming decades are widely understood. Several demographic changes will increase the number of older persons with disabilities potentially requiring care will be accompanied by a decline in the number of people available to provide care to them.

Older people, like everyone, need many different types of support at different times and for differing periods. These can include income assistance, accommodation, healthcare, rehabilitation support, personal care, psychological or behavioural support, and social interaction. Older people needing help rarely require only one form of help, and their needs will often increase over time. Some of the conditions associated with advanced age become progressively worse—for example, Alzheimer's disease—but there are often interventions that, if made in time, can greatly benefit older people. Short-term rehabilitation and support, for example, can improve or restore independence. Ultimately, however, the emphasis in treating older people with chronic conditions is often necessarily on caring rather than curing.

Older persons care has several characteristics that both connect it to, and distinguish it from, health care. Much of elderly care is about social functioning. It provides the help needed to cope when physical and mental decline impairs the capacity to perform everyday activities such as eating, bathing, dressing, shopping, and managing money. These declines can be the consequence of diseases such as osteoporosis, cardiovascular illnesses, multiple sclerosis, and Alzheimer's disease, but aged care has been principally about managing and reducing functional impairments rather than managing disease processes. A great deal of older persons care has tended not to involve highly technical medical services that need to be provided by specialist physicians or registered nurses. Instead, services have been provided by relatively low level-trained staff members who account for most paid carers.

Older persons care needs to connect with primary and acute care. People with long-term care needs are not necessarily sick and do not necessarily require intensive medical services most of the time, but they tend to see the doctor more often and are frequent users of acute care services. Consequently, coordination and integration with the medical care sector is important to meet the needs of older people with disabilities. The receipt of older persons care services is intensely personal and can involve intimate tasks like assistance with going to the toilet, bathing, and dressing over extended periods.
Such care becomes integral to how people live their lives. In Greece, as in most European countries, there are different types of long-term care provisions, both formal and informal. Formal long-term care is typically

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provided by a qualified workforce and may be delivered in different settings (residential care, formal homecare, or semi-residential care). Informal care is typically provided by someone from the care receiver's social environment (e.g. a family member, friend, or neighbour) and the provider is not hired as care professional.

Population ageing has significant implications for care and support systems. The need increases with age and is especially prevalent among the very old. With an increasing number of older people, the need for specialised care is therefore set to rise. Among those aged 65 or over, 47.8 % have disabilities[27]. These people are protected by the UN Convention on the Rights of Persons with Disabilities (UNCRPD) to which the EU and all Member States are party. A key challenge will thus be to meet the growing demand for accessible and good-quality long-term care services, in particular given labour shortages in the long-term care sector. At the same time, the declining share of the working-age population will make it more challenging to finance ageing-related spending, including for long-term care, thus putting the sustainability of current welfare systems at risk, and increasing the risk of poverty for those in need of care and their families.

In the context of ageing societies, a key challenge is to provide adequate, accessible, and affordable formal care services to those who need them. With a significant increase in demand ahead, already today, many people in need cannot access or afford them. Barriers to ensuring equal access to adequate long-term care include high financial costs; a lack of social protection or private insurance coverage; geographical disparities or even shortages in supply; a lack of information; complex administrative procedures; and lack of support to informal carers. Public expenditure on long-term care is projected to rise more quickly than on other social policy areas, including healthcare and pensions. Although public spending on long-term care is currently low in many Member States, including Greece, significant increases are projected in view of population ageing and the corresponding rise in demand. The projected expenditure increases are unsurprisingly even larger for many Member States when allowing upward convergence in long-term care policies. Financing such expenditure will pose new challenges since, with increasing life expectancy and a shrinking working-age population, the EU will go from 3.3 to only 2 working-age people for every person aged 65 or over during the next 30 years[28]. These developments

[27] Eurostat: self-perceived long-standing limitations in usual activities due to health problem by sex, age and labour status

[28] Eurostat population projections

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underline the need for Member States to ensure fiscally sustainable foundations for long-term care systems to enable them to meet older people's needs today and in the future.

Based on the available data of OECD, in 2016, there were less than one (i.e. 0.1) formal long-term care worker per 100 people aged 65 and over in Greece, compared to 3.8 long-term care workers for EU-27. Note should be made of the fact that, in Greece, women represent 95.8 % of the total number of formal LTC workers[29].

Greece has a high use of informal care provision and public long-term care is projected to increase from 0.2 % of GDP in 2019 and 0.4 % in 2030 to 0.6 % in 2050, implying a tripling of expenditure by 2050, but from a much lower level. At the same time, the costs of informal care are also expected to increase over this period due to the increase in the ageing of the population, and these also need to be included when looking at current and future expenditure on long-term care in Greece.

3.9 Informal Care and caregivers

Greek society considers it as an obligation of family members to take care of older members and members in need of additional special care. Therefore, informal care inside the family, provided by either relatives, or by professional caregivers (mainly by legal or illegal immigrants living in the country) plays a key role in meeting current needs.

The displacement of migratory flows before the 1990s led to a major change in care delivery. The immediate availability of relatively low-cost immigrant caregivers offers a solution which is at the same time affordable and compatible with prevailing views, although problems related to communication and culture often occur. The percentage of migrants working in the provision of support services to households is very high in Greece (20.5%) compared with other countries (in the United Kingdom it is at 2% and in the US only at 1.2%).

Indeed, older persons with disabilities can often benefit from care in the home. A study[30] has estimated that nearly 70 per cent of these will need some form of long-term care. The study projected the average total duration of long-term care use for older adults who turned 65 in 2005 to be 3 years. It further estimated that 1.9 years of

[29] OECD, Health at a Glance 2019: OECD Indicators, OECD Publishing, Paris, 2019. https://doi.org/10.1787/4dd50c09-en
[30] Sonnega, A, Faul, JD, Ofstedal, MBeth, Langa, KM, Phillips, JWR, Weir, DR, The Health and Retirement Stydy, Int J Epidemiol, 2014

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this care would be spent at home, with approximately 0.5 years of formal (paid) care and 1.4 years of informal care (e.g. from a spouse or partner, family member, or friend), and the remaining 1.1 years spent in long-term care facilities. Also, the analysis of data indicates that among all older households aged 65 and over with functional limitations, 54 percent received some form of help. The vast majority of this was unpaid/informal help, most of which came from family caregivers. Only 8.2 percent who reported receiving assistance got it from formal, paid sources.

Research data indicates that care for older persons is ten times more likely to be covered through informal networks than through the labour market in Greece, while obviously poorer people are supported mainly by other family members compared to those who are in better financial condition[31]. Greece continues to suffer from a lack of a clearly formulated strategy and policies regarding the regulation of informal care and the support of informal carers. Indeed, there are currently no provisions concerning in-kind benefits and in-cash support for carers. Nevertheless, Law 4808/2021/19-06-2021, which is the transposition of the EU Directive on Work-Life Balance defines for the first time the concept of informal carer as an employee who provides personal care or support to a relative or person who resides in the same household as the employee and who needs significant care or support for a serious medical reason. Apart from the fact that long-term care in Greece relies heavily on informal care services, it appears that the job of professional carer has not received any recognition yet. It lacks any specific regulation and legislation that would ensure that appropriate standards of provision, quality assurance arrangements, staff ratios, staff training, etc., are put in place. This, in turn, implies that there are neither specific working conditions nor specific types of employment contracts for those employed in the formal care sector. Employment contracts in the sector vary, depending mainly on the specialisation of the carer (social worker, nursing staff, etc.) and on whether a public or a private agency employs the carer.

Informal caregivers play a critical role in the care for older persons in Greece. They are considered resources within the social care system as they take care of persons in need relieving in this way, the official welfare state from its obligation to provide appropriate support. Despite these, caregivers are prone to psychosocial diseases and lack proper support to help them in their exhausting daily routine. Thus, informal care can be physically and mentally demanding, leading carers to often feel exhausted, lonely, and strained. Therefore, support from health care and social service systems is essential to empower informal caregivers to provide care at home. In Greece,

[31] OECD, Health at a Glance 2019: OECD Indicators, OECD Publishing, Paris, 2019. https://doi.org/10.1787/4dd50c09-en

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the only support services available to carers are those provided by a small number of NGOs, offering – among other things – information, practical advice, psychological/emotional support, and training. Most of these services target informal carers of persons suffering from specific diseases, such as dementia or Alzheimer's disease and – to a lesser extent – blindness and cancer. It is rather evident that the capacity of such services can hardly meet the numerous needs of informal carers across the country.

Nevertheless, the provision of informal care is not always covering existing, increasing needs. There is a great need for a more comprehensive formal care policy, and many European countries invest resources towards home care as this contributes to maintaining the independence of the people and is preferred by both recipients and their families.

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Chapter 4: Findings

4.1 Focus groups – interviews

Qualitative data for the scope of the study were collected from focus groups with professionals from the welfare sector and mainly with state representatives, seniors' non-governmental organisations, stakeholders, and others providing services at the field of care and support for older persons with disabilities.

Here the main areas of concern, emerged in the focus group:

Accessibility and information. All focus group participants initially perceived accessibility to the services as a major need in the sector. The need to increase both the amount and accessibility of information about existing services, in general, was a concern mentioned by participants. Many indicated that they would not know where to look for information about activities or services. They also expressed particular concern for older persons with disabilities who would be first time users of services, as they tend to have a difficult time accessing the services they need.

Quality of services. Most of the participants expressed concern for increasing efforts to improve the overall quality of current services and programs offering support and care for older persons with disabilities. They must be more supportive towards the inclusiveness of beneficiaries and not only to be structures of medical care. The lack of evidence-based qualitative criteria for the operation of the services for older persons with disabilities was also highlighted by several participants.

Supported living. Emphasis was given to the importance of supported living assistance, which included increasing the provision of a range of services and ensuring their accessibility. Suggestions included increasing the availability and affordability of additional care and health services at supported living schemes, such as SYD. There is a strong interest in a new legal framework to define the regulation status for those who are interested in developing SYD for residents with additional needs. Participants linked the operation of these services with the will of the State to increase the monthly reimbursement of the resident. They indicated significant concern over the perceived lack of affordable housing. They noted that affordable housing is a particular concern since it is not an easy task to rend a flat offering

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Supported living services to older persons with disabilities. They all suggested that the Greek State should provide incentives to owners to rent their flats as a SYD.

Informal carers. Participants highlighted concerns about the status of informal caregiving responsibilities for older with disabilities, pointed out such concerns and felt that more assistance is needed for those who are acting as caregivers for their ageing parents. In addition, an interesting finding came out. The services offering support programs for older persons with disabilities are often inadequate. Service users are at a high risk of being isolated from the community, of low quality of life, and sometimes even of neglect and abuse by carers. All participants mentioned the need for advocates who would ensure a higher quality of care for this population and help reduce the frequency of older abuse.

Coverage of services. A concern was also raised that, although more and more older persons with disabilities will need specialised care services as they get older, existent services cannot fully cover the needs of the population. There is a lack of such services available nationwide, especially in rural areas. In these areas, the availability of services cannot cover the current needs. Thus, the State and especially local and regional authorities must play a more active role in implementing programs for this vulnerable group.

Luck of information. Another point raised is that there is not enough and sufficient information about the services offered. There is a perception that most of the care is provided by some old-fashioned institutions and chronic illness – care units. This mindset must be changed, and is the role of the State, the Ministries to be the pioneers needed to set up a new reality for the sector. Public authorities responsible for care services offered to older persons with disabilities should facilitate ensure better communication among all relevant actors and promote a more positive image of older people in society.

Raise voices. There is another finding from the focus groups that indicated that services for older persons with disabilities should encourage their active involvement and, where appropriate, also their families, advocates and informal carers should be involved in the planning and delivery of services. The provision of services should encourage the beneficiaries, regardless of their disability status, in

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determining their personal needs and keeping control of the support they receive. Specialised care and assistance should be provided by skilled and competent workers with a decent salary and stable working conditions. Employees rights should be respected and protected by confidentiality, professional ethics, and professional autonomy. Opportunities for continuous training and improvement should be available to all carers. At this point, all agreed on the need for the development of a personal assistance program, especially as an action to support persons with disabilities to have an inclusive life.

Cooperation. A conclusion of the focus groups emphasised that the development of quality services for older persons requires the active participation and cooperation of all key-players both public and private: ministries, local authorities, service users, families and their informal carers, user organisations, service providers and their representative organisations and other stakeholders. This collaboration is essential for creating a continuum of services that meet both individual and local needs, for the efficient use of resources and experience, as well as to achieve social cohesion. Such partnerships are essential for the promotion of age-friendly communities.

4.1.1 Best Practices

Most of the focus groups participants reported having either personal experience with the programs provided to older persons or a theoretical approach that the most efficient for supporting overall the needs of older with disabilities are those of “Help at home” and “Supported living residences”. While they acknowledged the necessity of changes needed for the competency of these two programmes, they expressed a common preference for their efficiency at the ground.

The “Help at Home” programme has achieved results for older persons population but needs to be scaled up to benefit older persons with disabilities and even persons with intellectual or developmental disabilities. It needs constructive actions by the Greek State to improve the care outcomes of its beneficiaries. There is no need to “reinvent the wheel” but with certain actions to improve its performance. The programme enriches efforts for community living for older persons with disabilities as they get services at their place. The main components of the programme considered as positive and additionally its sustainability enabling to gather it as a best practice. The “Supported living residences” (SYD), satisfy the relative provision of UNCRPD about the right of inclusive living for all, regardless their disability status. The effectiveness of the programme and its core elements have

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achieved an overall positive outcome for service users. As the demand for additional care services provided at this program increases, more older persons with disabilities will benefit. The expert staff as well the positive assessment of the SYD can ensure its sustainability of services provided to its residents.

4.2 Recommendations

Disability is a multidimensional situation, and therefore, any interventions should not be carried out in fragments and without sufficient information on the real situation of people with disabilities. The Social Care system should support the availability and accessibility of older persons' care including people of diverse backgrounds and needs.

Some basic recommendations for the development of a more comprehensive support system for older people with disabilities include the following:

- The development of independent counselling and information centres for older persons with disabilities, their families, care professionals and service providers.

- The development of training programs based on quality principles for care staff and the informal caregivers.

- The development of a comprehensive framework for establishing new services of care for older persons with disabilities, including policies for vulnerable adult protection, financial guidelines, a code of conduct and guiding principles.

- The legal recognition of the profession of carer needs to be a policy priority. This can provide more opportunities for their professional development, their training and lifelong learning. At the same time, informal carers of older people with disabilities should have certainty that they will receive timely and high-quality supports.

- The development of specific new programmes and services for older with disabilities. In addition to mainstream services, older with disabilities require access to specific care programs and measures, such as rehabilitation and support services, including access to assistive technologies that improve functioning and independence. A range of well-regulated assistance and support services in the community can meet needs for care, enabling older with disabilities to live with dignity.

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- The development of a wider range of residential services that satisfy the diversity of disability at older stages of life. This will allow them to choose a living arrangement and service package that is tailored to their own specific needs. The challenge for policymakers is to ensure that public and private financing mechanisms will respond to this growing diversity and flexibility according to the choices and preferences of service users.

- Regulate service provision by introducing care service standards and by monitoring and enforcing compliance.

- The development of standards and mechanisms that will promote advocacy, provide complaint mechanisms for beneficiaries, guarantying the right of autonomy and independence and in particular the right to make decisions about their care and the quality of their lives and the right to social participation.

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Conclusions

In the present study is a first approach on the issue of care, support, and health provision for older persons with disabilities, mainly developmental disabilities in Greece. Older people with disabilities and developmental disorders constitute a large category that is closely related and permeates the entire range of services provided to older persons. It concerns a large part of social expenses and actions in social/health policy. As a thematic, it is also linked to social policy and welfare and is directly related to issues of social solidarity and social security. The main concern of the study was to raise and highlight some issues for further investigation and analysis regarding the existing policy, prospects and needs for an effective social protection framework for older persons with disabilities.

In Greece, long-term care, and support for older persons with disabilities remain an underdeveloped policy area, given that there are no sufficient and pluralistic services ensuring overall coverage. There is a minimum of care services provided to older persons, but they are not clearly addressing the needs and special characteristics of older persons with disabilities. There is a need for an accurate action to develop a substantial set of measures of the care and support for older persons with disabilities. This becomes even more critical given the pressure imposed by the rapidly ageing population and the increased number of older persons with disabilities. Services run by the public sector such as "KIFI", "KAPI", "Help at Home" as well programs run either by public or private sector such as “KDIF”, "SYD" should be assessed and then further developed keeping their positive features and extending the supportive and inclusiveness components.

A further development of current provisions to older persons with disabilities for care and health should be based on the protection and promotion of the rights of the people who require support and care. The rights of older people with disabilities who are seeking or receiving elderly care should be enshrined in legislation to leave no doubt about the importance placed on these rights. This rights-based approach should guarantee access to the supports and services that an older person is needing based on the core human right described mainly at UNCRPD.

Care Services for older persons with disabilities should address in a timely and flexible manner the changing needs of each beneficiary, with full respect for their personal integrity, to improve their quality of life, as well as ensuring equal access to care. Besides, this is in line with the relative provisions of article 25 of the UNCRPD.

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Services should consider the physical, cultural, and social prospects of older persons with disabilities, their families, or other important people in their lives. In addition, the services should ensure that they provide staff with the necessary support, resources, and amenities to work in this way. Person-centred services should be guided by the needs of the older with disabilities and, where appropriate or as required, by the needs of their relatives or carers.

Defining the quality of services provision for older persons with disabilities remain under examination. This is correlated to the fact that most of the relative services are based on informal care system.

Although there is a minimum of care services provided to older persons, they are not clearly addressing the needs and special characteristics of older persons with disabilities. That is a challenge for the Greek State to determine the needs and develop a frame of legislation to regulate the sector, ensuring high standards of provision, quality assurance arrangements, staff skills, financial and social security support, etc. There is a clear need for developing a comprehensive system of care provision for older persons with disabilities that will coordinate the support of long-term formal and informal care. The development of a legal frame of support and counselling, both for beneficiaries as well caregivers are particularly important.

Support should be available at home by developing long-term care services and support community-based, individualised settings, telecare/telehealth services for long-distance support, in rural and insular areas, emergency support services, supported living facilities for persons with disabilities with higher support needs. For what concerns elderly persons, a system including benefits, day-care availability, help at home and participation in social activities, and housing solutions are in place. Nevertheless, some services are missing, and others would need innovation to increase their possibility for choice, community living and participation in society. There is a lack of community-based and home-based services, and of formal home care services by home care takers properly trained and certified.

The services should be available in support of everyone in need, as well as the freedom of choice offered within the community, whenever possible. The availability of services can be ensured by a strategic planning, the financing and design of services by public authorities with the support of service providers to provide an adequate care and support reliable services at older with disabilities. They should be easily accessible to anyone

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who may request them. Older with disabilities should get access to the service as well as custom information and communication.

Services must be developed in a comprehensive way that reflects multiple needs and capabilities of the older persons with disabilities and persons with intellectual or developmental disabilities.

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ANNEX I

A) National Legislative Framework on Social Care

Social Care General

- **Law 2646/1998 (Greek Government Gazette A 236)** "Development of the National Social CareSystem and other provisions".
- **Article 14 of Law 3106/2003 (Greek Government Gazette A 30)** *"Reorganisation of theNational Social Care System and other provisions"*
- **Law 3094/2003 (Greek Government Gazette A 10)** *"Greek Ombudsman and other provisions"*
- **Law 3961/2011 (Greek Government Gazette A 97)** *"Amending Law 3126/2003 on the criminal liability of ministers and other provisions".* It concerns the observance of the National Registerof Child Protection.
- **Article 9 of Law 4109/2013 (Greek Government Gazette A 16)** *"On the abolition and merger of legal entities of the State and the wider public sector; setting up a General Secretariat for the coordination of government business and other provisions*". Existing Social Care Units established under Law 3106/2003 (Ά 30) shall be integrated as decentralised services (branches) into twelve (12) new Public Law Bodies governed by public law (Social Welfare Centres), established under Article 9 of Law 4109/2013 (Greek Government Gazette, Ά 16).
- **Law 4445/2016 (Government Gazette, Series I, No 236)** *"National Mechanism for the Coordination, Monitoring and Evaluation of Social Integration and Social Cohesion Policies, arrangements for social solidarity and implementing provisions of Law 4387/2016 (Greek Government Gazette Ά 85)".*
- **Law 4455/2017 (Greek Government Gazette A 22):** *"National Register of Cargo Workers, National Register of Private Social Care Bodies and other provisions*"**.** Article 7 stipulates the placement of non-profit organisations, such as charities, non-profit foundations, non-profit civil societies, NGOs, NGOs recognised by special legislation, branches of international NGOs, which provide social care services within the meaning of the Law, under the supervision and control of the Ministry of Labour and Social Affairs.

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B) National Legislation Elderly and Long-term Patients

a. Day Care centres for the Elderly

i. **Ministerial Decision P1B/G.P.oik.14951/2001 (Greek Government Gazette ΄B 1397)** *"Conditions for the establishment and operation of Centres for Day Care of the elderly by Municipal Companies referred in Article 277 of the Municipal and Community Code. MunicipalBusiness, Associations of Municipal Enterprises and non-profit bodies governed by private law".*

ii. **Joint Ministerial Decision 18011/oik.31414/2011 (Government Gazette ΄B 1231)** "*Amending Joint Ministerial Decision No 0.18975/οικ.3.3113/21.10.2010 (Greek Government Gazette ΄B 1683) "Management, Evaluation, Monitoring and Control System - Action Application Process*" 'Measures to support the elderly and other persons in need of assistance to enhance the employability of indirect beneficiaries' and (b) 'Measures to promote social cohesion and improve the quality of life for the elderly and people in need of help', in the context of the National Strategic Reference Framework for the 2007-2013 programming period.

b. Non-Profit Elderly Care Centres

- **Ministerial Decision P4B/oik. 4690/1996 (Greek Government Gazette B 833)** *"Conditions forthe establishment and operation of non-profit elderly care centres".*
- **Ministerial Decision P1G/oik. 129673/2009 (B 2190***) "Amending and supplementingMinisterial Decision Π1Γ/οικ.81551/2007 (Government Gazette B 1136) on conditions for the establishment and operation of elderly care centres established by private for profit and non- profit organisation".*
- **Ministerial Decision D27/oik.7603/329/2013 (Greek Government Gazette B 745) "Amending** *Ministerial Decision 81551/25 − 6 − 2007 (Greek Government Gazette, B 1136 "Determining the conditions for the establishment and operation of the elderly care centres by private for profit companies or non for profit elderly care organisations".*

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c. Housing Assistance Programs for the Elderly

- **Ministerial Decision G3/oik.2615/22.05.1985 (Greek Government Gazette (B 329)** *"Approvalfor the implementation of the Housing Assistance program for uninsured and economically weak residents aged 65 years or more that are proven to be deprived of a house".*

d. Social Solidarity Benefit for the Uninsured Elderly

- **Ministerial Decision 10034/24237/655/2016 (Greek Government Gazette B 2401)** *"Defining the supporting documents and other necessary details for the payment of the Social SolidarityBenefit for the Elderly".*

C) Help at Home Programme

- **Article 2 of Law 4041/2012 (Greek Government Gazette A 31)** *"Ratification of the LegislativeAct on emergency measures to implement the 2012-2015 Medium-Term Fiscal Strategy Framework and the 2011 State Budget' and the Legislative Act on urgent matters relating to the implementation of Law 4024/2011 on pensions, a single salary scale - labour reserve and other provisions for implementing the 2012-2015 medium-term fiscal strategy framework andof the Ministry of Administrative Reform and e-Governance, the Ministry of Interior, the Ministry of Environment, Energy and Climate Change and the Ministry of Education, Lifelong Learning and Religious Affairs on the implementation of the 2012-2015 medium-term fiscal framework, and other provisions, as extended by* **127 Law 4199/2013 (Greek Government Gazette A 216)**, as extended by article 64 of Law No 4277/2014 (Greek Government Gazette A 156).

- A new extension of program **Article 49 of Law 4351/2015 (Greek Government Gazette A 164)**, *"Pastures in Greece and other provisions",* as extended by Article **69 of Law 4430/2016 (A 205)** on Social and Solidarity Economy and Development of its bodies and other provisions, asrenewed by Article **153 of Law 4483/2017 (Greek Government Gazette A 107**) on arrangements for the modernisation of the institutional framework for the organisation and operation of the Municipal Water Supply and Sewerage Companies (DEYAs) — arrangements relating to the organisation, operation, finance and staffing of local authorities — European Groups for Territorial Cooperation

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— Citizens' register and other provisions, as extended by article **91 of Law 4583/2018 (Greek Government Gazette A 212).**

- New amendment to the Help at Home program No.1847/166 11.12.2018.

D) Supported Living Residences

- **Joint Ministerial Decision Γ4a/Φ.201/1791/1998 (Greek Government Gazette B 517)** "*Conditions for the establishment and operation of Supported living shelters for persons with Special needs and* its amendment (Greek Government Gazette, B 579/1998).
- **Joint Ministerial Decision P3B/FGEN/G.P.oik.3394/2007 (Greek Government Gazette B 74)***"Conditions for the establishment and operation of supported living shelters for persons withdisabilities".*
- **Joint Ministerial Decision D29a/F.ΘΕΣΜ. /GP26275/1048/22-1-2014 (Government Gazette B172)**. *Establishment of a specialized daily allowance for Supported living Shelters for persons with disabilities".*
- **Joint Ministerial Decision D12/GP.oik.62866/1832/2018 (Greek Government Gazette B5582**) "Conditions for the establishment and operation of *supported living shelters for persons with disabilities".*
- **Joint Ministerial Decision D12/GP.oik. 13107/283 (Greek Government Gazette B 1160)** "Conditions for the establishment and operation of *supported living shelters for persons withdisabilities".*

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ANNEX II

Two focus groups were conducted in December 2021. The first focus group consisted of seven (7) persons and the second group was comprised of six (6) professionals. Participants were representing a variety of relative to the study disciplines (Directors of services targeting older persons with disabilities, psychologists and other relevant professionals, board members, policy makers). The Discussion was guided around the main research topics, those of exploring the quality of current services provided to older persons with disabilities or with intellectual/developmental disabilities as well as the weak and strong points of these. Furthermore, the aim of the focus groups was to gain insight knowledge and search any positive initiatives at the field.

The section of the study presents findings from the focus group discussion s highlighting the main points of what participants said in response to open-ended questions.

Due to pandemic covid-19 measures, both focus groups were conducted through an online platform. The time duration for each group was about 2h.

The participants represented key players of the services related to the study subjects and their selection was based on criteria such as experience, employment status, the diversity, passion about the topic and decision-making level.

The participants were:
three (3) directors from NGO's caring and supporting persons with disabilities,
two (2) presidents of social care entities,
two (2) seniors at ministerial level,
one (1) social worker,
one (1) CEO of a company at professional care,
one (1) psychologist,
one (1) public servant at the field of services quality control at the regional level,
one (1) lawyer,
one (1) vice-mayor with experience developing care services for a municipality.

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EASPD is the European Association of Service providers for Persons with Disabilities. We are a European not-for-profit organisation representing over 20,000 social services and disability organisations across Europe. The main objective of EASPD is to promote equal opportunities for people with disabilities through effective and high-quality service systems.

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