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### **SOCIAL PROTECTION OF PEOPLE WITH DEMENTIA IN HUNGARY**

**Abstract.** This paper presents the results of the study of main features and current state of social protection of people with dementia in Hungary. At present, the population of Hungary is rapidly aging and is decreasing quantitatively. Social and demographic changes as well as the increase of life expectancy affect the provision of social services for the population of Hungary. The aim of the paper is to provide an overview of social services delivered to persons with dementia in Hungary. To achieve this aim the following tasks were defined as to be solved: to characterise the organisation of social support for persons with dementia and the services provided. The study object – social policy of Hungary. The study subject – social services provided to the persons with dementia. The following research methods have been used: – theoretical – the secondary analysis of scientific-research sources on the problem under consideration has given the possibility to systematize and generalize the available data on current state of the problem; – empirical – observations and interviews with scholars and practical social workers have given an opportunity to analyse the Hungarian experience in social services provision to persons with dementia. The data gathered allowed to conclude, that in Hungary dementia is not considered to be among the social and healthcare priorities. In accordance with the Hungarian legislation, persons with dementia are not considered to be «people with disabilities» and therefore they are not eligible for financial or social benefits as provided to other persons with disabilities. Although the law provides for the state funding of normative day-care fees, daycare facilities are not available. Respite homes and long-term care institutions are very limited in number. State supported home-care is limited to the provision of meals at a low cost. Private institutions are inaccessible due to high costs. Adequacy, accessibility and availability of services in general do not respond to the needs of either people with dementia or the family carers.

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## Introduction

Dementia is a very uncomfortable issue for the broader public, society. It's a form of diversity which hardly anyone wishes to celebrate. It should be recognised that the majority of today's elderly are healthy and active. However, it is also clear that within the rapidly growing numbers of elderly people, there is a sizable minority of those who are ill and frail. And unless there is a spectacular medical and social breakthrough, the number of persons suffering from dementia will also continue to increase.

In 2005, the European Commission published a Green Paper which opened a Europe-wide debate on demographic change. In this document as well as in documents and debates, which followed, the Commission stressed the need to appreciate the positive aspects of population ageing, i.e. longer life expectancies, and discussed policies which could increase the participation of older workers in economic life ([Green Paper, 2005](#)). It is not just about delaying retirement. It concerns a conscious re-structuring of societies, of health care and social services, workplaces and job markets, of streets and public spaces, and of the systems of general education and specialised training. A larger population of very old persons, a minority of which probably suffer from dementia, have different needs than in the past. The emphasis is shifting from purely material aspects of well-being to those of human rights and human dignity, of highest achievable autonomy coupled with social interaction, with survival as a social being. This development is highly relevant for the issue of dementia because all people, including those with a cognitive deficit, have human rights; all should have their human dignity respected; and all have emotional needs which should be met by other human beings ([Špidla, 2007](#)).

It is clear from the findings that social support of people with dementia and their carers varies considerably from one country to another. While some countries may have a wide range of services available to most patients, in others there is a scarcity of adequate and/or affordable support services, such as home help, day care, respite care and of course also residential care. The same is true as regards the support provided by governments, be it as care allowances or other entitlements such as tax refunds or direct payments to pay for services, for employing a person to provide home care services or for necessary home adaptations ([Andersson, 2007](#)).

A closer look at the problem suggests Member States of the European Union set the aim to constitute responsible societies. Thus, they are to face the problem of dementia, as it involves human suffering; because it concerns important aspects of the way in which our societies are organised; and, finally, because it is growing and set to grow further in the decades to come.

Hungary is a state in Central Europe, a member of the EU with a population of about 10 million people. During the laying of the foundations, specialists saw social work in this country as an auxiliary profession that could mitigate the harmful sequences of social and economic changes, and contribute to the structural transformation of society. Over the past decade, the social sector has grown into a large service sector, employing nearly 100,000 people. Almost one fifth of them work as practical social workers in the social welfare sector.

This sector is the most low-paying among the Hungarian state social services. The rethinking of social work in Hungary began in 1989.

*The analysis of recently rapidly growing scientific literature* demonstrates that nowadays, thirty years later, the Hungarian practitioners and scholars refer to the problems of comprehension of history, development, formation, place and role of social work in modern Hungarian society, perspectives of social work and social services provision in Hungary (Budai, 2010; Bugarszki, 2014; Krémer, 2014; Németh, 2014; Szabó, 2014; Szoboszlai, 2014). Despite the considerable interest of scientists to the above-mentioned problems, we believe that the further research in this area may include the issue of social protection of persons with dementia in Hungary. *The aim of the paper* is to provide an overview of social services delivered to persons with dementia in Hungary. To achieve this aim the following *tasks* were defined as to be solved: to characterise the organisation of social support for persons with dementia and the services provided. *The study object* – social policy of Hungary. *The study subject* – social services provided to the persons with dementia.

### **Methodology**

The following *research methods* have been used: – theoretical. The secondary analysis of scientific-research sources on the problem under consideration has given the possibility to systematize and generalize the available data on current state of the problem. The conducted literature review is based on a wide range of trustworthy sources with a particular focus on reports of European Commission, textbooks, journals, and scholarly articles on selected research area. The following databases have been used after introducing the keywords (social work in Hungary, healthcare in Hungary, social work with persons with dementia in the EU/ Hungary): DBLP; Google Books; Google Scholar; JSTOR Search; Scopus, Vernadsky National Library of Ukraine; Web of Science; – empirical. Observations and interviews with scholars and practical social workers have given an opportunity to analyse the Hungarian experience in social services provision to persons with dementia.

### **Research results and discussion.**

#### **Social and demographic changes in population**

At present, the population of Hungary is rapidly aging and is decreasing quantitatively. Social and demographic changes as well as the increase of life expectancy affect the provision of social services for the population of Hungary.

Aging of the population is a long-term tendency that began in Europe a few decades ago. The tendency is displayed in the transformation of the age structure of the population and is reflected in an increasing share of the elderly, as well as in the declining share of working-age persons in the total population. The population of the EU-28 on 1 January 2016 was estimated at 510.3 million people. The share of the population aged 65 years and over is increasing in every EU Member State, EFTA country and candidate country, and Hungary is not an exception (see Table 1) (Eurostat. *Statistics Explained*, 2017). Within the last decade (2006–16), an increase of 2.4 percentage points was observed for the EU-28 as a whole.

Table 1.

**Population age structure by major age groups, 2006 and 2016**  
(% of the total population)

	0-14 years old		15-64 years old		65 years old or +	
	2006	2016	2006	2016	2006	2016
European Union-28	16.0	15.6	67.1	65.3	16.8	19.2
Belgium	17.1	17.0	65.7	64.7	17.2	18.2
Bulgaria	13.4	14.0	69.2	65.6	17.5	20.4
Czech Republic	14.6	15.4	71.1	66.2	14.2	18.3
Denmark	18.7	16.8	66.1	64.3	15.2	18.8
Germany	14.1	13.2	66.7	65.7	19.3	21.1
Estonia	15.0	16.1	68.1	64.9	16.9	19.0
Ireland	20.5	21.9	68.5	64.9	11.0	13.2
Greece	14.9	14.4	66.6	64.3	18.5	21.3
Spain	14.5	15.1	68.8	66.1	16.6	18.7
France	18.5	18.5	65.1	62.8	16.4	18.8
Croatia	15.8	14.6	66.7	66.2	17.5	19.2
Italy	14.1	13.7	66.0	64.3	19.9	22.0
Cyprus	19.4	16.4	68.5	68.4	12.2	15.1
Latvia	14.5	15.2	68.5	65.1	17.0	19.6
Lithuania	16.6	14.7	67.2	66.3	16.3	19.0
Luxembourg	18.4	16.5	67.5	69.3	14.1	14.2
Hungary	15.4	14.5	68.8	67.2	15.8	18.3
Malta	17.1	14.2	69.1	66.7	13.8	19.0
Netherlands	18.3	16.5	67.5	65.3	14.3	18.2
Austria	15.9	14.3	67.6	67.2	16.4	18.5
Poland	16.2	15.0	70.4	69.1	13.3	16.0
Portugal	15.9	14.1	66.8	65.1	17.4	20.7
Romania	16.9	15.5	68.4	67.0	14.7	17.4
Slovenia	14.1	14.8	70.3	66.7	15.6	18.4
Slovakia	16.7	15.3	71.5	70.2	11.8	14.4
Finland	17.3	16.3	66.8	63.2	16.0	20.5
Sweden	17.3	17.4	65.4	62.8	17.3	19.8
United Kingdom	18.0	17.7	66.1	64.4	15.9	17.9
Iceland	21.8	20.0	66.5	66.1	11.7	13.9
Liechtenstein	17.4	14.9	71.1	68.6	11.6	16.5
Norway	19.5	17.9	65.8	65.6	14.7	16.4
Switzerland	16.0	14.9	68.0	67.2	16.0	18.0
Montenegro	20.4	18.3	66.8	67.6	12.8	14.1
Former Yugoslav Republic of Macedonia	19.5	16.7	69.4	70.3	11.1	13.0
Albania	25.7	17.7	65.7	69.5	8.6	12.9
Serbia	15.7	14.4	67.1	66.6	17.2	19.0
Turkey	27.0	24.0	66.3	67.7	6.7	8.2

In an attempt to look at future trends for population ageing, Eurostat's latest set of population projections (EUROPOP2015) were made covering the period from 2015 to 2080. In EUROPOP2015 the EU-28's population is projected to increase to a peak of 528.6 million around 2050 and thereafter gradually decline to 518.8 million by 2080, with population tendency to continue to age (from 29.3 % of 65 years or over in 2016 to projected 52.3 % by 2080) (Figure 1.) (Eurostat. [Statistics Explained](#), 2017).

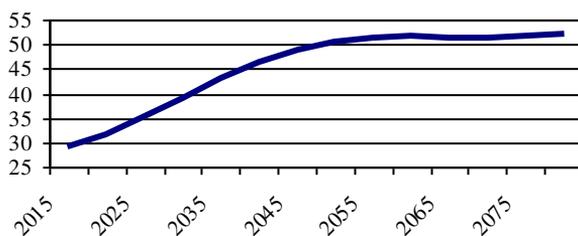


Figure 1. Projected old-age dependency ratio, eu-28, 2016-2080 (%)

Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

World Health Organisation ([World Health Organisation, 2015](#)) provides the following key facts on dementia: (i) Worldwide, 47.5 million people have dementia and there are 7.7 million new cases every year. (ii) Although dementia mainly affects older people, it is not a normal part of ageing. Very rarely dementia is found in people younger than 60 years old. The probability of dementia increases with age: about 5 % of people suffer from dementia in the age group of 65-74 years old, and about 30 % of people suffer from dementia in the age group of 85 years old and over. (iii) Alzheimer's disease is the most common cause of dementia and may contribute to 60-70 % of cases. It can also be caused by a variety of diseases and injuries that primarily or secondarily affect the brain, such as stroke. (iiii) Dementia is one of the major causes of disability and dependency among older people worldwide. (iiiii) Dementia has physical, psychological, social and economical impact on caregivers, families and society

Dementia has significant social and economic implications in terms of direct medical costs, direct social costs and the costs of informal care. In 2010, the total global societal costs of dementia was estimated to be US\$ 604 billion. This corresponds to 1.0 % of the worldwide gross domestic product (GDP), or 0.6 % if only direct costs are considered. The total cost as a proportion of GDP varied from 0.24 % in low-income countries to 1.24 % in high-income countries.

Dementia is overwhelming for the families of affected people and for their caregivers. Physical, emotional and economic pressures can cause great stress to families and caregivers, and support is required from the health, social, financial and legal systems.

People with dementia are frequently denied the basic rights and freedoms available to others. In many countries, physical and chemical restraints are used extensively in care facilities for elderly people and in acute-care settings, even when regulations are in place to uphold the rights of people to freedom and choice.

Eurostat's latest data (last update: 06-02-2018) demonstrate that the share of deaths of Hungarian residents related to dementias including Alzheimer is constantly increasing (see Table 2, Table 3) (Eurostat, 2018).

Table 2.

*Deaths of residents related to dementias in EU-28*

	2011	2012	2013	2014
European Union-28	198327	225258	239005	248220
Belgium	5440	6501	6681	6307
Bulgaria	171	233	185	141
Czech Republic	1770	1990	2280	2404
Denmark	3042	3138	3284	3433
Germany	26068	29999	34843	34955
Estonia	83	92	86	111
Ireland	1222	1499	1742	1904
Greece	335	496	417	1066
Spain	26486	29376	29074	31897
France	32739	36994	36675	35996
Croatia	555	691	682	775
Italy	24607	26531	26159	26567
Cyprus	147	173	166	179
Latvia	149	161	219	218
Lithuania	170	192	255	245
Luxembourg	150	205	220	209
Hungary	2504	2784	2 905	2951
Malta	132	82	123	143
Netherlands	9152	10415	13405	12492
Austria	1267	1619	2158	1923
Poland	2193	2254	2434	2175
Portugal	1650	1745	3724	4125
Romania	1378	1550	1639	1918
Slovenia	100	109	112	149
Slovakia	757	1532	1055	1350
Finland	6194	7047	7530	8101
Sweden	6909	7691	7762	7859
United Kingdom	42956	50158	53 191	58625
Iceland	165	171	185	203
Liechtenstein	9	6	9	12
Norway	2503	2759	2722	3019
Switzerland	5178	5742	5909	5765
Former Yugoslav Republic of Macedonia	:	:	:	2
Serbia	896	1 066	1246	1316
Turkey	6445	7 921	9250	10691

Table 3.

***Deaths of Hungarian residents related to dementias including  
Alzheimer by gender***

	2011		2012		2013		2014	
	male	female	male	female	male	female	male	female
Hungary	852	1652	869	1915	932	1973	935	2016

An appropriate and supportive legislative environment based on internationally accepted human rights standards is required to ensure the highest quality of service provision to people with dementia and their caregivers.

### **Organisation of social support for persons with dementia**

On the basis of the evidence (Fedor & Patyán, 2010) currently available, it seems fair to suggest that two systems (the system of social protection and social care; the system of social workers training) have been formed in Hungary simultaneously. The system of social protection and social care was based on old institutional traditions, inherited the features of centralisation, hierarchy, paternalistic and the medical-social approach. In this context, social services were provided through the development of institutional capacity.

K. Tausz's (Tausz, 2006) findings lend support to the claim that the Hungarian social policy developed typically to the post-Soviet EU member states. The Hungarian researcher defines this policy as a transitional social policy with no clear priorities for the development of well-being. Political discussions about social work in this country define it as «liberal social work», although it has always been closer to social-democratic social work in its values than to liberal social work.

Separate discussions are being held among scholars about social work as a practical activity, which in their opinion, detains clients in a dependent position, using social benefits. Experts demonstrate the increasing bias and skepticism against the real effectiveness of social work in this country. A new type of statism reacts to social problems at the state level, and not at the level of professionals.

In 2012 the provision of care in long-term residential social institutions was taken over from the county municipalities by the State, and the social institutions that were previously in county operation were transferred to state maintenance. In 2013 the State also took over the responsibilities related to the operation and maintenance of specialised residential social care institutions providing accommodation for people living with disability, psychiatric patients and people struggling with addictions (National Social Report. Hungary, 2014).

In this situation, social service providers are getting new roles. Social work, organised by the state, becomes more structured with moral problems and care provision, therefore, some professionals show greater skepticism about social work, and sometimes considering, that they do not need a diploma «for the delivery of food to the elderly». In fact, the state policy intensifies the process of deprofessionalisation (Patyán, 2015).

The following institutions and bodies are responsible for social support of persons with dementia in Hungary: the Ministry of Social Welfare and Labour, the Ministry of Health, local authorities and the Charity Service of the Roman Catholic

Church. The State also cooperates with the private sector in the sense that the State provides financial support to each person receiving care in a state/private institution. Cooperation between the State and NGOs is only formal. It is limited to certain public events and does not cover social services.

Provision of social support to persons with dementia is regulated by: Act No. LXXX of 1997 on Persons Entitled to Social Security Benefits and Private Pensions, as well as the Funding for These Services (the Social Security Act [Törvény LXXX, 1997](#)); Act No. II on Social Security of 1993, which specifically mentions the organisation of day care centers and specialised care homes for persons dementia ([Natlex, 2018](#)); Act on Budget of the Republic of Hungary, which provides higher monthly normative state funding (approximately 30 % more) for nursing homes (either state or private) for people with dementia than for other homes for the elderly. Although the law provides for the state funding of normative day-care fees, day-care facilities are not available because local authorities do not set up day care centres on the basis of these low fees. The normative fees do not cover the full cost of weekly day care stipulated by law ([Alzheimer Europe. Hungary, 2007](#)).

### **Services and support provided to persons with dementia and their carers**

(1) Day care. There are no day-care facilities for people with dementia in Hungary.

(2) Respite care. Respite care in the home is not available from the State. A limited number of private service providers offer this service but at a high cost.

Short-term residential respite care is available but only privately and at a high cost. In exceptional circumstances, respite care can be provided (subject to payment) in the long-term care wards of hospitals.

To provide long-term residential care the state/local authorities has opened nursing homes for a very limited number of people with dementia with waiting lists ranging from 3 to 7 years. By law, 80 % of the person's pension is taken to pay for this service. However, this amount is not sufficient to cover the monthly fee for the care provided. Consequently, families pay extra monthly fees.

There are only a few privately owned nursing homes in Hungary. Entrance costs (i.e. a down payment) (between EUR 12 000-20 000 plus the monthly fee for care EUR 600-700 net) make them inaccessible to most Hungarians.

The Charity Service of the Roman Catholic Church also provides long-term care services in seven care units (for approximately 200 people).

(3) Palliative care. Palliative care at home is not available. It is available in palliative care centres for people with cancer only and is partly funded by the state.

(4) Home help and personal assistance.

Home help is one of the basic mandatory social services provided by local authorities to care for people, usually older persons, who are unable to care for themselves. Meals are one of the basic social services provided by local authorities, ensuring at least one hot meal a day for people in need of social assistance who are unable to provide this for themselves or whose carers are permanently or temporarily unable to do so. Local authorities must also provide meals for people who are unable to organise their own meals in any other way because of their age or state of health (Act

III of 1993, Section 62). Due to financial limitations, many local authorities are unable to provide this service even though it is stipulated by law.

It is possible to obtain assistance with personal hygiene and assistance with eating and drinking from social workers who are employed by the local authorities, but at the full cost for them. Assistive devices are available, but the State does not compensate anything towards the cost. Monitoring in the home via alarm systems (special tele-alarm systems) are not available in Hungary for people with dementia. Some local authorities operate such systems for the elderly but they are not suitable for people with dementia. The State either does not provide services due to financial limitations and despite legal provisions on: assistance with mobility; assistance with shopping; assistance with housework; assistance dealing with incontinence; companionship/social activities; home adaptation/transformation; occupational therapy/ergotherapy.

Long-term home care is available from local authorities but only for a very limited number of people with dementia. Of the 24-hour daily care necessary, a maximum 2-hour service is offered against payment. Generally speaking, the carers who provide this service are not trained for the task and are unwilling to stay with the person with dementia alone. Thus, in about 99% of cases, long-term home care is provided by family carers, who need psychosocial support and proper training. In the absence of social support from the State, carers have to bear the burden alone and many end up mentally and physically exhausted with financial difficulties. The Hungarian Alzheimer Society operates a help-line and provides free of charge personal consultations on request to family carers throughout the year, but counselling for people with dementia is not available. There are no provisions for holidays either for people with dementia or carers. The Hungarian Alzheimer Society provides training for carers whenever funding is available ([Alzheimer Europe. Hungary, 2007](#)).

(5) Work/tax related support for people with dementia and their carers.

There are no protective measures for people with dementia who are still in paid employment. In fact, a person who has been diagnosed with dementia is often dismissed from his/her job. People with dementia are not entitled to any tax refunds or benefits, any direct payments to pay for social services or for employing a person to provide home care services, any financial assistance with home adaptations etc. as in Hungary dementia is not considered a disability.

Carers are not entitled to paid time off work or flexible working hours to enable them to care for someone with dementia. Those who take unpaid time off work to care for a relative may easily lose their jobs and would not be entitled to any benefits. If carers are entitled to care benefits, the period of time spent caring is taken into account when calculating the pension. However, it is rare for people caring for someone with dementia to be entitled to care benefits.

## Conclusions

The following institutions and bodies are responsible for social support of persons with dementia in Hungary: the Ministry of Social Welfare and Labour, the Ministry of Health, local authorities and the Charity Service of the Roman Catholic Church. The State also cooperates with the private sector in the sense that the State provides financial support to each person receiving care in a state/private institution.

Cooperation between the State and NGOs is only formal. It is limited to certain public events and does not cover social services.

As under the current Hungarian law, people with dementia are not regarded as «disabled», they are not entitled to any of financial or social benefits, which are granted to other disabled people. Although the law provides for the State funding of normative day-care fees, daycare facilities are not available because local authorities do not set up day-care centres on the basis of these low fees. The normative fees do not cover the full cost of weekly day care stipulated by law. Respite homes and long-term care institutions are very limited in number. State supported home-care is limited to the provision of meals (in many towns and villages) at a low cost. Private institutions are inaccessible due to high costs. Adequacy, accessibility and availability of services in general do not respond to the needs of either people with dementia or the family carers.

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## СОЦІАЛЬНИЙ ЗАХИСТ ОСІБ З ДЕМЕНЦІЄЮ В УГОРЩИНІ

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**Анотація.** В статті розглянуто основні риси та сучасний стан соціального захисту осіб з деменцією в Угорщині. На сьогодні населення Угорщини швидко «старішає» і кількісно зменшується. Соціальні та демографічні зміни, підвищення очікуваної тривалості життя впливають на соціальні послуги для населення Угорщини. Мета статті – схарактеризувати соціальні послуги, що надаються особам з деменцією в Угорщині. Було визначено такі завдання: охарактеризувати організацію соціальної підтримки та соціальні послуги, що надаються особам з деменцією. Об'єкт дослідження – соціальна політика Угорщини. Використано наступні методи дослідження: – теоретичний – аналіз наукових джерел з проблеми дослідження для систематизації та узагальнення наявних даних, виявлення сучасного стану досліджуваної проблеми; емпіричні – спостереження, бесіди з науковцями та практичними соціальними працівниками, які дали можливість проаналізувати угорський досвід надання соціальних послуг особам з деменцією. Отримані дані дозволили зробити висновок, що в Угорщині деменція на сьогодні не вважається одним із пріоритетів соціального захисту та охорони здоров'я. Відповідно до чинного законодавства Угорщини, особи з деменцією не розглядаються як «особи з інвалідністю», а тому не мають право на отримання фінансових або соціальних пільг, які надаються іншим особам з інвалідністю. Для таких осіб в Угорщині відсутні центри денного догляду, а кількість місць в установах довгострокової опіки є дуже обмежена. У забезпеченні довгострокової інституційної опіки задіяна державна система охорони здоров'я та соціального захисту населення. Функціонують приватні установи довгострокової опіки, але в обмеженій кількості і за дуже високу оплату. Державна підтримка на дому обмежується доставкою їжі. Таким чином, вважаємо, що в Угорщині адекватність та доступність послуг не відповідають потребам осіб з деменцією та їх піклувальникам. Перспективи подальших досліджень пов'язуємо з вивченням проблеми соціального захисту інших категорій населення в Угорщині.

**Ключові слова:** старіння; особа з деменцією; піклувальник; соціальні послуги; Угорщина.

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