



# Innovation for Dementia in the Danube Region

## INDEED WP7

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*GA4 meeting  
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A stream of cooperation

# WP7 – Policy

## Social Cluster Association

### Hungary



Programme co-funded by the  
European Union

## Social Cluster Association

- **NGO: small civil organization since 2007**
- **Committed experts**
- **Without employers**
- **Lack of financial support**
- **Language barrier**
- **Membership by Alzheimer Europe**





# Interprofessional approach



## Our team

- **Ráczné Németh Teodóra**
- **Vajda Norbert**
- **Hegedűs Péter**
- **Vajer Péter**
- **Sebastian Bonis**
- **Kocsis Judit**
- **Turcsikné Várallyai Zsuzsanna**
- **Egervári Ágnes**



## Major gaps in dementia care in the Danube region

- Lack of knowledge and skills of relevant occupational groups (general physicians, nurses, psychologists, occupational therapists, physical therapists, pharmacists)
- Lack of mutual understanding, collaboration and coordination among these groups
- Lack of dementia-specific facilities (e. g. day centres, special care units)

## POLICY

- **What and how to do?**
- **Key persons are stakeholders**
- **What are their expectations?**

That's why we start also with the policy

## Overall goal of WP7...

- ... is simple: to provide **useful** and „user friendly” Policy Recommendation Catalogue at the final stage of the INDEED project for certain countries’ decision makers
- Promote the outcomes of the INDEED project among relevant decision makers - **sustainability**
- It is a gradual construction – from GA1 through GA2 and GA3 till GA4 -**involvement**







## RESULTS OF THE QUESTIONNAIRE

- Stakeholders of different countries form a heterogeneous group
- Most of them meet people living with dementia indirectly
- **Majority of the stakeholders agreed on categorizing dementia as a disability**
- **In most cases the legal framework is really fragmented or does not exist at all**

## RESULTS OF THE QUESTIONNAIRE

- **They do not find the services related to dementia are adequate**
- **They do not think their country ranks dementia as a priority among other policies**
- **To their opinion family caregivers are not integrated to the social care system at all**

## RESULTS OF THE QUESTIONNAIRE

### Stakeholders think

- that people working in the care system within dementia issue are not supported enough by their government
- that the presence of dementia in trainings and education in general is not satisfactory
- also the preventive health care programs do not focus on the topic of dementia

## STAKEHOLDER'S SESSION

- **Based on questionnaire**
- **Interactive**
- **Get involved to create  
common ideas**
- **Lot of work with enjoyment**





## Urgent issues concerning to dementia

Urgent issues	What is missing?
<ul style="list-style-type: none"><li>➤ Lack of support for the family caregivers</li><li>➤ Lack of financial resources</li><li>➤ Lack of medical staff</li><li>➤ Lack of qualified employees</li><li>➤ Lack of cooperation</li><li>➤ Lack of dementia centres</li><li>➤ Lack of private services</li><li>➤ Lack of education</li><li>➤ Lack of nursing homes</li><li>➤ Lack of early diagnoses</li><li>➤ Lack of awareness of dementia</li></ul>	<ul style="list-style-type: none"><li>➤ Specific trainings for caregivers</li><li>➤ Specific regulations</li><li>➤ Good practice</li><li>➤ Budget</li><li>➤ Multidisciplinary team</li><li>➤ Collaboration of GP's</li><li>➤ There is no well-developed day care centres</li></ul>

## POLICY ASSESSMENT REPORT

The subsequent key points in improving dementia care, among them as follows:

- improving education and training of healthcare professionals on dementia,
- enhancing the collaboration among healthcare professionals and,
- increasing the importance of dementia care in the national policies.

**INDEED**

# **I WILL DO FOR THE POLICY THAT**

- work on the impact of digital technology
- support Alzheimer Society in developing training programmes,
- the Dementia Theme gets into the focus of the next campaign on PR,

## I WILL DO FOR THE POLICY

- I'll contact professionals and colleagues from Ministry of Health talk to them about topics, we were talking about and try to find out the way how to bring important things to the life...
- I will communicate with people around me and talk to them about problems, difficulties and obstacles that people with dementia and their families are facing. I will try to raise awareness about dementia.
- transfer the knowledge and good practice examples from other European countries

so that to show: **people with dementia and their relatives are not forgotten**

Policy Scoping Event is a **direct action** to provide further information for the improvement of the INDEED project's educational intervention program



**Pilot Actions**

Policy Scoping Event is an **indirect action** to involve policymakers and to ensure the durability and sustainability of the project outcomes.



**Policy Safari**



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# Mean goals of the Policy Safari

**to involve** the given nations' relevant policymakers,

- initiation of **personal** negotiations with them and inform them about the INDEED project results.
- The strengthening of the national and regional **networks** of professionals will greatly support the dissemination goals of the project.
- Provide clear input information for the PRC
- The policymakers will be asked to provide advice on whether INDEED matches national dementia strategies or plan.

## Method

How to reach the right policymakers?

Addressing policymakers, who have had contact with the INDEED project and have participated in the General Assembly in Bratislava and/or Munich, with the support of INDEED partners.

1. Creation of detailed country-specific **interview guide**
2. **Contacting INDEED Partners** (4+1 countries) and check whether the policymakers are still available
3. **Contacting policymakers** with the assistance of partners
4. Time management

# Impact of the COVID-19 pandemic

- The personal interviews were not possible from March 2020, hence we have to reschedule the task.
- During the autumn of 2020, we have to change our original plan and start to organize online interviews via Skype or other online meeting services.
- Finally, we organized 2 personal interviews in Hungary and **5 online interviews**: 2 in Slovenia and 1 with Bulgarian, Romanian and Slovakian representatives of the ministries.

## Main findings

**the process of developing the Dementia Action Plan, main stages, cooperating institutions**

- **family, social, health sectors work together**
- **Professionals in all three sectors have continuously communicated the need to treat dementia to official representatives**
- **All three sectors have a role to play:**
- **Experts from all disciplines affected by dementia had the opportunity to respond or make a constructive suggestion**



## Main findings 2.

### The challenges by developing a Dementia Strategy

- The participation of the Ministry of Finance - more resources must be provided in the care system.
- It is necessary to review social capacities, what opportunities we currently have, to what extent capacity expansion is needed
- Diagnostic and early detection
- Dissemination of social knowledge and acquaintance of the symptoms with the relative is also essential, e.g. family control
- Financial resources must be allocated to the families and the carers too
- A detailed register of the people who live with dementia is necessary to allocate resources and handle the care them (even they are living at home or in institutions).

## Main findings : about INDEED e-learning platform

- **Campus: useful way to inform....**
- **share the informations**
- **the interdisciplinary aspect**
- **Connect part can help the experts with different background to change their habits and understand each other easier**
- **Coach : the state has to provide the care**
- **How to keep the higher standards**

## POLICY RECOMMENDATION CATALOGUE

### How to improve the Quality of life for people with dementia? Make Dementia a Health Priority!

#### CHALLENGES

Dementia has a profound life-changing impact - not only on the person with dementia, but their carers, family members and friends. As it is an incurable and indolent illness, it has huge financial and social expenses.

#### SOLUTION: INNOVATION FOR DEMENTIA IN THE DANUBE REGION

The main objective of INDEED is to improve dementia care in the Danube region and contribute to the implementation of national dementia strategies with the scope of enhancing the quality of life of people with dementia and their carers. Partners from 10 countries create an information and skill-building intervention for institutions involved in dementia care and their members or employees, including health and social services, professional associations, governmental authorities, public administrations and private enterprises.

#### THE APPROACH

Three modules addressing competences, collaboration and innovation were developed, as follows:



##### CAMPUS

providing knowledge and skills



##### CONNECT

promoting collaboration



##### COACH

stimulates entrepreneurial innovation in dementia care

## THE OUTCOMES

### Educate!

Make dementia a part of the curricula of relevant professions

Put a focus on general physicians.

Highlight the importance of non-pharmacological interventions and social components.

Emphasise the importance of timely diagnosis and make practical supportive material. Share the international good practices.

Complement professional training by educating the civil society.

### Connect!

Incorporate and support interprofessional shared learning and training in dementia strategies and plans among general doctors, physical therapist, neurologist, care givers, social workers, nurses, etc. health and social care professionals

Strengthen the role of social work as a key component of collaborative care.

Involve non-medical associated occupations groups in special dementia trainings.

Promote the formation of therapeutic teams including patient organisations.

### Innovate!

Support initiatives which expand the spectrum of services for people with dementia.

Announce best-practice examples of services and support their roll-out nationwide

Facilitate entrepreneurial initiatives that enable independent living for people with dementia



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# Thank you for your attention

## köszönöm!



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