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TETRAS

Enhancing transfer of transversal skills for social inclusion

Improving competences of educators
Focus: successful social inclusion of people with cognitive disabilities for the transfer of transversal skills

26 November 2024- 9.30-14.30- Veneto Region Brussels Office, Av. De Tervueren 67



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Support of the Committee Inclusive Territories Environment and Health





YOUNGCARE

RELIEF FOR YOUNGER PEOPLE IN NEED OF CARE AND THEIR INFORMAL CARERS

YoungCare

Strategies to Support Informal Caregivers and Young People in Need of Care

November 25, 2024

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Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Education and Culture Executive Agency (EACEA). Neither the European Union nor EACEA can be held responsible for them.



- Erasmus+ project



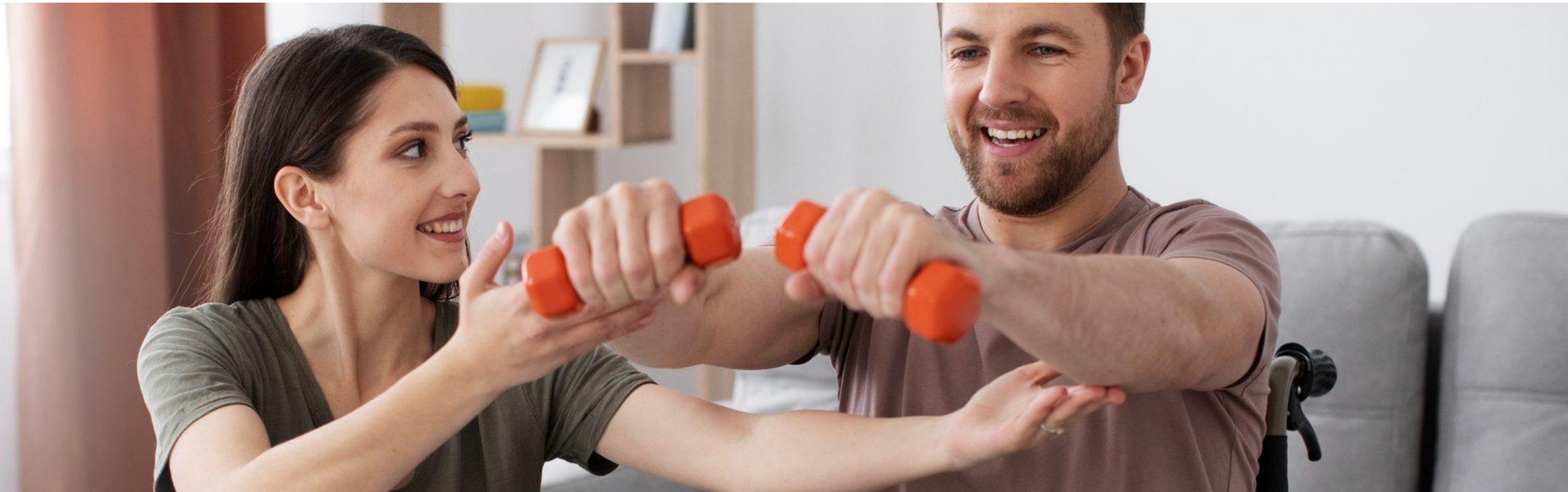
Co-funded by
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- December 2022 – July 2025
- 6 partners from 5 countries:
 - SHINE 2Europe (Portugal)
 - ISIS Institut für Soziale Infrastruktur gemeinnützige GmbH (coordinator)
 - AFEdeMy – Academy on Age-Friendly Environments in Europe BV (Netherlands)
 - Vytauto Didžiojo Universitetas (Lithuania)
 - Cooperativa Assistenza Dissabili Infermi Anziani Infanzia (Italy)
 - Paritätische Projekte gemeinnützige Gesellschaft mbH (Germany)



Why YoungCare?

“There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver.” Rosalynn Carter



OUTCOMES

YOUNGCARE GUIDE

Orientations for young adults in need of care and their informal caregivers.

E-LEARNING OFFER

Accessible content focused on practical issues for informal caregivers and young adults in need of care.

RECOMMENDATIONS

Policymakers and formal caregivers



YOUNGCARE GUIDANCE



WHO IS IT FOR?

Informal caregivers and young adults with care needs



HOW WAS IT DEVELOPED?

- Desk research in 5 countries (education, employment, housing, health and social care systems, political situations, and examples of good practice) – 5 National Reports
- 52 Interviews (24 with informal caregivers, 17 with adults with care needs and disabilities, and 11 with experts)



YOUNGCARE GUIDANCE



WHAT CAN BE FOUND?

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Initial diagnosis & understanding the situation

A family member or close relative becoming dependent can be a very shocking experience as it changes both the life of the person in need of care from one day to another and that of those who suddenly have to turn into informal carers. On the other hand, a diagnosis can also confirm existing signs and symptoms and give the disease a concrete name. Accepting the situation may be challenging.

Many of our interviewees described the diagnosis as the beginning of a process during which many things had to be renegotiated, in the relationship as well as in the organisation of everyday life. Understanding the diagnosis is an important step in taking action in this new situation.

Namia (Germany)

Several respondents said that they were overwhelmed by the news and found it difficult to take the first steps. The example of Namia (54) illustrates this. She is the mother of a severely mentally disabled son (33) who she cares for. She found it very difficult to accept his mental disability. However, only after accepting his disability was she able to start looking for help. The care system (social and medical specialist services) was completely unknown to the family until then. She also criticises the expectation of counselling centres whereby clients have prior knowledge of the support services. Finding out about the system was also difficult for her because of her limited language skills due to her migration background. Providing care was a learning process for her.

What are the first steps to take?

There are quite a few challenging things. At first it is hard to accept that a close person has a life-changing medical condition. Understanding and accepting the situation is helpful in order to plan your next steps and reach out for help. This, of course, is easier said than done. Support and help aren't only dependent on your ability to respond fast or not. As shown in the above example, getting to know the healthcare system and available support services can be quite difficult. As discouraging as this may sound, it shows how important it is to accept the situation and inform yourself and reach out for help as soon as possible. Of course, the situation differs from country to country. Bureaucratic hurdles, difficulties in obtaining an official recognition of the need for care, and claiming financial support are often stressful and time consuming.



Info

In many regions there are self-help groups and counselling services, where informal caregivers can get in touch with others in the same situation. Informal caregivers can find these groups and services useful because the situation described above applies to many people who have to deal with care systems and regulations. These groups can help with open questions and provide emotional support. You can find what is on offer here:

LITHUANIA:

- The [website of the Ministry of Social Security and Labour](#) provides information on the provision of social services to various groups of people, including persons with disabilities and their relatives;
- As far as the provision of **social services** is concerned, a person can apply directly orally, in writing, by mail or e-mail to the municipality of the person's (family's) place of residence or to a social service institution that provides and/or organises social services.

GERMANY:

- **"wir pflegen! e. V. – Die Stimme der pflegenden Angehörigen in Deutschland"** - "Wir-Pflegen! e.V." is an organisation representing the interests of family caregivers throughout Germany as well as self-help organisations. You can find details about it [here](#). Among other forms of support, they provide an app called **in.kontakt** to help caregivers connect with each other online.

VIDEO PILL 1: Why YoungCare? And what is it?

Scene background: The words in bold appear with visuals in the background of individuals with disabilities facing challenges in accessing education, employment, and social activities. Images might include people in wheelchairs navigating inaccessible streets, individuals facing discrimination in employment settings, and others struggling to participate in social events due to lack of accommodations.

Narrator:

Lithuania: social poverty and exclusion among people with disabilities exceed 35%

Italy: Approximately 7 million Italians are involved in informal caregiving

Netherlands, there are about 5 million informal caregivers, with 460,000 feeling overwhelmed.

Portugal has an estimated 800,000 informal caregivers, with 25% being classified as "full-time" caregivers.

Germany: 73.6% of individuals in need of care are cared for at home.



YOUNGCARE GUIDANCE



WHAT CAN BE FOUND?

Lack of comparable data:

- Variability in the total number of informal caregivers (ICs) versus those officially recognised.
- Informal caregivers make up 5-10% of the population in different countries.

• Differences in legal frameworks and processes:

- *Lithuania*: Still working on policies to support informal caregivers
- *Portugal*: introduced a Statute for Informal Caregivers in 2019 and is reviewing it.
- *Netherlands*: Beginning to address informal caregivers within academic settings.

• Support system for informal caregivers

- **Self-help groups** (Lithuania, Germany).
- **Centre for independent living**: Offers support for adults in need of care (Portugal).
- **Care triangle model**: Encourages effective collaboration among formal caregivers, informal caregivers, and care recipients (Netherlands).

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WHO IS IT FOR?

Informal caregivers and young adults with care needs



HOW IS BEING DEVELOPED?

- Analysis of National Reports (desk research + interviews)
- Peer review by consortium partners
- Review by associated partners
- Testing with target audience



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WHAT WILL BE AVAILABLE?




- **Content in 6 languages (EN, PT, DE, NL, IT, LT)**
- **General content**
- **National content**

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WHAT WILL BE AVAILABLE?

 Map

 House & Living

 Leisure & Mobility

 Participation & Employment

 Care & Support

Home Adaptations

Housing Options

Inhouse help



What kind of modifications are available to adapt your home to new needs? In the areas (kitchen, sleeping, hygiene)

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Services



Good Practices



List of Materials

RECOMMENDATIONS



WHO IS IT FOR?

- Policy makers
- Formal caregivers



HOW WILL IT BE DEVELOPED?

- 5 National Reports (education, employment, housing, health and social care systems, political situations, and examples of good practice + results from 52 interviews)
- Inputs from Dutch Associated Partners
- Desk research on European Legislation
- Online European roundtable with experts




RECOMMENDATIONS – NEXT STEPS



HOW WILL IT BE DEVELOPED?

- Online European roundtable with experts (1st session: November 20, 2024)

? What recommendations should we make to policymakers and professional caregivers to enhance support for informal caregivers ?




Can you select a spokesperson to briefly share this session's highlights?

1

What are the biggest challenges informal caregivers face in your region?

Lack of relief services	Are there any other existing organizations?	Coordinate work or other obligations with the care they need
Lack of informal caregivers	Intermittent issues, spillover	finances and giving informal care
They feel informal support is not organized to suit activities	lack of professional caregivers	Lack of support and funding from security support
	Numerous different legal claims	

2

What are the biggest challenges informal caregivers face within national health and social care systems?

lack of formal care givers	Lack of systemic and system support	They are not recognized fully within national system
hard to get in	Social network	There is no network between them
lack of adequate funding	Bureaucracy	

3

How can professional caregivers collaborate with informal caregivers to enhance care quality?

other informal caregivers training on specific tasks	Guidance for informal caregivers	Link informal caregivers could be a good opportunity to increase formal care activities
also use collaboration among professional caregivers, doctors and other care givers	Recognize and inform health care professionals	Train funding support from other sources
To organize joint events, actions, to attract and inform caregivers in different settings and possibilities	Recognize the position of the informal caregiver	

4

Are there good practices in health or social care systems that could serve as models?

strong care-giver informal caregiver		

5

What are the most urgent services that health or social care systems should provide to informal caregivers?

relief services	Emotional and mental health support
Smart home Technology Integration	Accessible housing Design
	Education and support on their own health care system
	Official and transparent support

6

What policies or legislative frameworks in your country - or others - have effectively supported informal caregivers?

Major legislation	

RECOMMENDATIONS – NEXT STEPS



HOW WILL IT BE DEVELOPED?

- Online European roundtable with experts

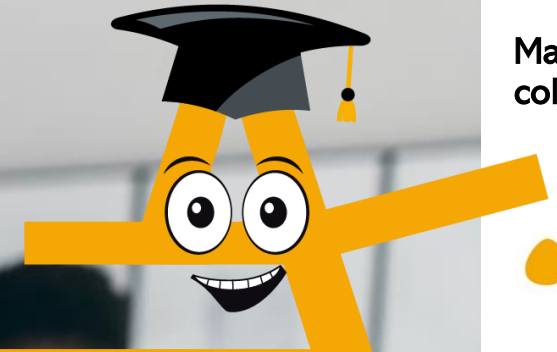
2nd Session – January 22, 2025, **12:00–13:30** CET:

- Compilation of work from the previous session
- Integration of recommendations based on prior discussions

Your expertise and participation are greatly welcomed!



Thank you for being a part of the experience and for staying with us.
Let's take a well-earned break and savor a festive lunch together."



TETRA-S Training Course

Made in collaboration with:



ERASMUS+ PROJECT

TETRAS

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