

Recommendations for Policy Makers



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Recommendations for Policymakers

Methodological Introduction on Adult Learning – Policy Makers

Responsible partner: Emphasys Centre (CY)

The chapter in brief: adult learning (formal and informal initiatives) is high on the agenda of European Union, because is the key to the personal development of the citizens and to active participation to community.

Education and the ability to continue learning are fundamental human rights. They are also key to the personal development of the citizens but are also key to the promotion of a more equal society, increasing democratic participation and reducing widespread inequalities. Taking this into consideration, adult learning (formal and informal initiatives) is high on the agenda of European Union.

At a national and local level, policy makers have a key role to play in order to promote adult learning opportunities and make it more accessible for everyone. To start with, it is important to understand the key characteristics of adult learners in order to be able to facilitate adult learning opportunities.

Knowles (1984) suggested 5 assumptions about the characteristics of adult learners:

✓ **Self-Concept**

As a person matures his/her self-concept moves from one of being a dependent personality toward one of being a self-directed human being.

✓ **Adult Learner Experience**

As a person matures, he/she accumulates a big collection of experience that becomes an increasing resource for learning.

✓ **Readiness to Learn**

As a person matures his/her readiness to learn becomes oriented increasingly to the developmental tasks of his/her social roles.

✓ **Orientation to Learning**

As a person matures his/her time perspective changes from one of postponed application of knowledge to immediacy of application. As a result, his/her orientation toward learning shifts from one of subject- centeredness to one of problem centeredness.

✓ **Motivation to Learn**

As a person matures the motivation to learn is internal.



Having already identified the characteristics of adult learners, it is important for key stakeholders to also be aware of the barriers and challenges adult learners face in relation to learning. According to the European guide for improving participation and awareness of adult learning (European Commission, 2012), there are three types of barriers to consider: *structural, situational and psychological*.

- **Structural Barriers**

This type of barrier is related to structural issues which are discouraging the participation of adults in adult learning such as lack of suitable programmes, lack of funding and/or not flexible educational system. As a result, in order to overcome these barriers policy makers should try to introduce operational changes and promote available options more widely.

- **Situational Barriers**

These are mostly challenges related to the individual circumstances of the learner such as child bearing responsibilities, mobility issues etc. Actions should thus aim at developing educational pathways and infrastructures suited to the needs of the target group.

- **Psychological Barriers**

These barriers are related to adults' life experiences and may be associated to negative experiences with schooling and education, lack of confidence, motivation and sense of worthlessness. As such, actions should aim to overcome those barriers, raise awareness about the benefits of lifelong learning and to increase the motivation to participate.

To sum up, adult education has the potential to contribute positively to the development of key skills and competences, and to counter inequalities, but all relevant stakeholders need to keep those principles and guidelines in mind when designing or delivering adult education training, in order to ensure maximum learner engagement and motivation.

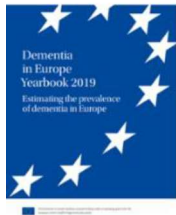
Introduction

Responsible partner: ASLTO3 (IT)

The chapter in brief: In order to face the global growing of dementia, policy makers are committed to develop comprehensive national and local dementia strategies, involving people with participative activities, supporting lobbies and networking on dementia.

Importance of Policies for People Living with Dementia

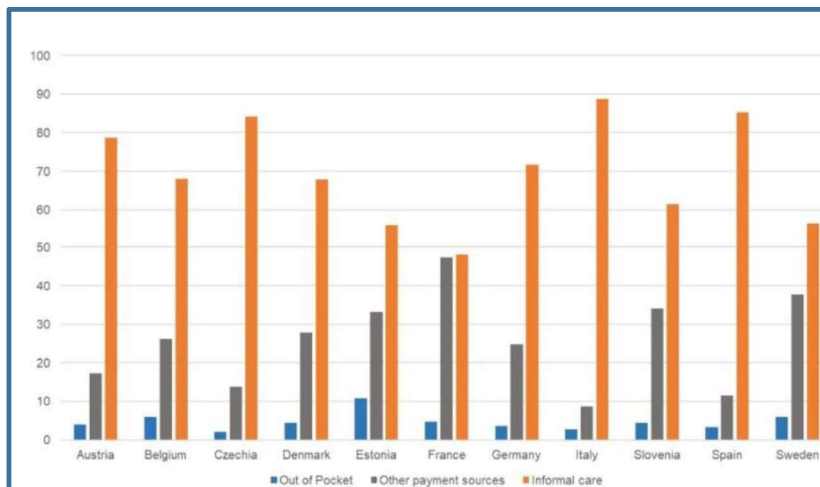
Dementia is a global emergency, a growing health and care issue, a challenge for ageing societies. These are words which are most commonly used to direct attention to the fact that estimations of the global prevalence of dementia predict increase in numbers of cases. As Europe is ageing and age being one of the main non-modifiable risk factors for dementia, projections show doubling in numbers of people developing dementia in the following years. This will have profound effects on people's lives, societies, communities, with pressure on the social and health care systems and impacting economies.



The Alzheimer Europe's Yearbook on Dementia in Europe^[1] provides an overview of prevalence estimates of the number of people with dementia in EU countries. The 2025 estimates show that the highest % of population living with dementia is expected for Italy with 2,44% of population, followed by Greece with 2,37%, while the lowest rates are estimated for Ireland at 1,27% and Cyprus at 1,26%.

For individual countries' profiles see the yearbook.

There is a need for understanding the costs of health care revenues for dementia not in terms of highlighting economic burden for countries, but in terms of directing health priorities and setting better management of funds. According to a study done by the National Institute on Ageing, National Institutes of Health (USA)[2], which calculated the economic costs of dementia, including both direct medical and social care costs and indirect costs of informal care, for 11 countries in Europe: average annual direct out-of-pocket costs per person living with dementia were lowest in the Czech Republic, Denmark and Sweden ranging from €700 to €950 and the highest being over €1.500 in Austria, Belgium, and Germany.



Share of direct out-of-pocket, informal care and direct public and private health and LTC insurance costs of dementia in 2018.

Figure source: [The Lancet regional Health – Europe 2022](#)

Such data are important for designing and planning strategies, building national health and social policies and legislation related to dementia. All stakeholders addressing the challenges dementia should be involved in an integrated approach to improve the quality of lives of people living with dementia and their families. Policies have to ensure possibilities for preventive measures, opportunities for education and life-long learning, timely diagnosis, support for family members and informal carers, fighting stigma and supporting dementia inclusive environments and initiatives.

The Glasgow Declaration, adopted in 2014 at the 24th Annual Conference of Alzheimer Europe, calls upon the European Commission to create a joint European Dementia Strategy and urges every country in Europe to:

- Develop comprehensive national dementia strategies with allocated funding and a clear monitoring and evaluation process;
- Involve people living with dementia and their carers in the development and follow up of these national strategies;
- Support national Alzheimer and dementia associations.

Amid these processes there must always be respect of the rights of people with dementia:

Glasgow Declaration 2014



"We think dementia should be higher on the EU agenda so we support the 'Glasgow Declaration' - European Working Group of People With Dementia

The European Working Group of People With Dementia (EWGD) strongly supports the Glasgow Declaration 2014.

"Every person living with dementia has the right to:

- a timely diagnosis,
- access quality post diagnostic support,
- person centred, coordinated, quality care throughout their illness,
- therapeutic interventions,
- be respected as an individual in their community"^[3].

Source: Alzheimer Europe, [Glasgow Declaration 2014](#)

More on prevention and general recommendations to manage health policies about dementia can be found at the [MYHAD Be connected MOOC](#).

References

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Chapter 1 - Nudges for Health Literacy about Dementia

Responsible partner: ASLTO3 (IT)

The chapter in brief: Policy makers can find information on how to increase health literacy about dementia within the community. Raising knowledge and skills about dementia is the first step to empower people, creating a sense of active and inclusive citizenship.

1.1 Health Literacy, Empowerment and Policy Makers

Health literacy is critical to empowerment because it enables people to make positive choices. Health literacy aims to provide people with cognitive and social knowledge and skills that determine individuals' motivation and ability to promote good health and activate themselves to find innovative solutions to the challenges of dementia in order to achieve the highest possible level of well-being (Kickbusch, WHO, 2013).

Low literacy is a potential health risk factor, but it can be mitigated by improving the quality of public communication about health and increasing societal awareness. Improving health literacy about dementia has benefits not only for people living with dementia and their caregivers, but a high literacy rate in the population benefits societies, in keeping with the idea that the more informed a community is about dementia, the better individuals can prepare, both for their own health and that of their family members or neighbors. An informed society provides all-around support.

Providing skills and educating people about dementia means making the environment inclusive and able to take concrete actions to support those living with dementia. Organizations have a responsibility to address health literacy. Policymakers and decision makers can empower people by lighting in them attention and knowledge with respect to the issue, so that then each person in his or her daily reality can make a difference.

Health literacy about dementia is the first step in achieving the goals cited in the National Dementia Plans or Strategies of different European countries and in the "[Alzheimer Europe Strategic Plan \(2021-2025\)](#)" and others, focusing on:

- Making dementia a European priority and health policy interventions
- Increased awareness, risk reduction and reduced stigma
- Implementation of strategies and interventions for appropriate care (tailor-made diagnosis, treatment focused on the individual and their specific needs)
- Support for dementia caregivers
- Dementia research and innovation
- Providing a voice to people with dementia and their caregivers
- Creation of an integrated dementia network and integrated management, research, care, and education



A FOCUS ON HEALTH LITERACY

DEFINITION

According to the updating US Health Department definition for 2030 (Santana et al. 2021), “*health literacy occurs when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions*”¹.

Different sides of health literacy could be taken into account:

1. the ability of the person receiving health information to **access, understand and use** that health information and make correct decisions to maintain and promote their own and others health (*personal health literacy*);
2. the ability of the person communicating health information to effectively **achieve understanding** (Wisconsin Health Literacy WHL, 2021);
3. degree to which organisations equitably **enable individuals** to find, understand, and use information and services to inform health-related decisions and actions for themselves and others (*organisational health literacy*) (Santana et al. 2021).

While the second point focuses on communication that may need to be tailored to individuals receiving the information, the third one underlines a **public health perspective**, addressing the environmental, political and social factors that determine health.

WHY improving health literacy

Benefits at individual level

- ✓ To empower people to prevent and/or manage chronic health conditions
- ✓ To increase independence or chance of remaining in a living situation longer
- ✓ To easily locate health services to turn to
- ✓ To reduce caregiver burden

Benefits at collective level

- ✓ To reduce economic spending on health care
- ✓ Increased likelihood of following preventive measures
- ✓ To reduce health disparities and achieve health equity
- ✓ To reinforce the individual's virtuous behaviour
- ✓ To build inclusive society

Why policy makers should care about it:

- ✓ To increase the quality of life and promoting education for healthy lifestyles.
- ✓ To boost the use of services in the territory by leveraging local networks
- ✓ To decrease public spending by optimizing resources on the community

1.2 How to Design Policies to Support Health Literacy about Dementia

Two important points should be taken into account, as outlined in the [WHO Guide: Toward a dementia plan](#) (2018):

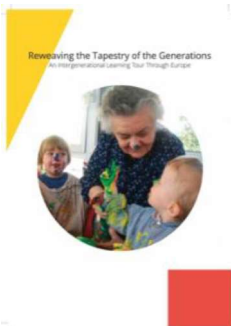
- “**Nothing is about us, without us**”: the engagement of people living with dementia is essential to ensure that their priorities are identified and effectively expressed. Policy-makers need to hear the direct and authentic voice of people with dementia and carers when faced with important policy decisions. For example, getting those living with dementia to participate at the Dementia Table.
- **There is no single solution**, but several actions that can be implemented in community with specific characteristics.
In the following paragraph, policy maker will find some good practices about **communication and networking**.

1.3 Communication actions

It is the responsibility of policy makers to ascertain what is to be communicated (the content of the information), but also how (the manner of communication). A few points of attention make all the difference:

1.3.1 Open communication actions to other targets: your targets are not only people with dementia and their caregivers. Communication about dementia is also targeted to young people and children of different age groups. Knowledge and awareness of dementia could also develop among future generations of adults and within families, fostering intergenerational exchange and spreading a culture of respect.





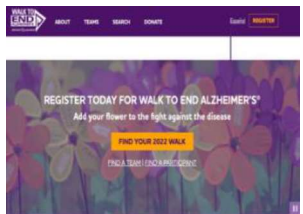
Reweaving the Tapestry of the Generations
Intergenerational Learning Through Europe

Experimental trials

of elderly and nursing home residents spending time with preschool or kindergarten children for mutual benefit: elderly well-being (as a sense of usefulness and meaningfulness), and preschool children's learning with an increase in solidarity and recognition of the value of older people ([see the European Lifelong Learning TOY Project \(2013\)](#)).

1.3.2 Use of active methodology: Health literacy is “embedded information”: as policy maker you might improve non formal learning settings to mature knowledge into competences, boosting active involvement of people. Make people feel part of the action and arise awareness on dementia! Active learning methods ask people to engage in their learning by thinking, discussing, investigating and creating, with practical application.






Workshop or public events on World Alzheimer's Day, events aimed at the entire citizenship could be organized, with workshops and laboratories to try to empathize and "put people in the shoes" of those living with dementia. See the Alzheimer's Marathon in USA [here](#) and in Italy [here](#).

1.3.3 Give the voice to people with dementia: Promote advocacy and direct testimony listening. Advocacy is the active support and advocacy by individuals who aim to influence public policy and resource allocation. The goal of advocacy is to ensure that the voice of the person remains at the centre of any action or decision.





Witnesses and caregivers should be involved in talking about dementia; listening to testimonies allows people to empathize and predispose them to acquire more health information. See the following video about an interview to Helen Rochford Brennan, member of *Irish Dementia Working Group* and of *European Working Group of People with Dementia*: [here](#).

Project Number: 2020-1-IT02-KA204-079434

1.4 Supporting the local networking to make integrated action

Any intervention to be effective and sustained over time should be carried out together, it gains relevance if done by coordinating between different entities (health care system, community, people with dementia and their caregivers, policy makers, private associations, etc). Policy makers should support local networks to foster the construction of supportive environments for those living with dementia.

1.4.1 Strengthen the training of health professionals and the engagement of adult educators, with a focus on technological innovation and the dissemination of evidence-based practices.



To know more:

For Adult's Educator (teachers, heads of Universities of Third Age, etc) see the [MYH4D MOOC](#) (Massive Open Online Course) and [MYH4D Community of practice](#)



For professionals and caregivers of people with dementia: see [Educational App for caregivers of people with dementia](#)

1.4.2 Implement tailored programs and services that aim to increase social integration: It means supporting actions on the ground that make people with dementia feel involved, give them the opportunity to maintain a connection with the community.



Dementia Friendly Community is an example of how training and building "Dementia Friendly" realities in cities help to build more caring communities that can independently make changes in daily life to be more inclusive [here](#).

Read also this paper to know more about implementation and scaling-up [here](#)

1.5 References

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- [6] US Department of Health & Human Services, Office of Disease Prevention and Health Promotion. Secretary's advisory committee on national health promotion and disease prevention objectives for 2030: Healthy People 2030 framework. <https://www.healthypeople.gov/2020/About-Healthy-People/Development-Healthy-People-2030/Proposed-Framework> . Accessed August 20, 2020.

Chapter 2 - Integrated Approach



Responsible partner: Zorg Kortrijk (BE)

The chapter in brief: *Integrated Care Approach means moving away from episodic care to a more holistic approach to health, care and support needs, that puts the needs and experience of people at the centre of how services are organised and delivered.*

Integrated Care Approach means moving away from episodic care to a more holistic approach to health, care and support needs, that puts the needs and experience of people at the centre of how services are organised and delivered. Ideally, this approach is person-centred. Person-centred care involves tailoring a person's care to their interests, abilities, history and personality. According to Alzheimer's Society key points of person-centred care are:

- Treating the person with dignity and respect
- Understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests
- Looking at situations from the point of view of the person with dementia
- Providing opportunities for the person to have conversations and relationships with other people
- Ensuring the person has the chance to try new things or take part in activities they enjoy.
- The person with dementia, family and caregivers should always be involved in developing a care plan based on person-centred care.

The person with dementia, family and caregivers should always be involved in developing a care plan based on person-centred care.

2.1. The Voice of the Person with Dementia

Inherent in the integrated approach, people with dementia are involved in decision-making. In terms of policy, people with dementia can be involved. Some examples are:

- The [Flemish working group for people with dementia](#) launched together with the Dementia Flanders Expertise Centre and the Alzheimer Liga Flanders, a strong appeal to policy. This resulted in the manifesto '[Hand in Hand](#)', written by people with dementia and their caregivers.
- [Advisory board dementia](#) in the Netherlands is a group of people with dementia who provide advice and knowledge, about what it is to live with dementia, to the Alzheimer Netherlands. That way they can do their job better as a representative and an advocate.
- [The European Working Group of People with Dementia](#) (EWGPWD)

But also at the municipal level, councils for the elderly can advise on policy and thus express the voice of the elderly (with or without dementia) to make the living environment more inclusive.

2.2. Dementia-friendly Environment

In addition to adapting the physical environment, creating a dementia-friendly environment also consists of involving people with dementia in society. By giving dementia more visibility and by providing training for e.g. municipal staff, shopkeepers the stigma around dementia will reduce and people with dementia will feel valued.

The WHO developed a [toolkit for dementia-friendly initiatives](#). The toolkit can be easily and effectively implemented by communities worldwide to raise awareness of dementia and improve the lives of those affected by the disease.

There are also various websites about which adjustments are possible in the home, transport, public buildings to make the environment more dementia-friendly. Examples of this are:

- [Hulpmiddelen bij dementie](#)
- [Dementia Enabling Environments](#)
- [Dementia-friendly environment checklist](#)

In addition to adjusting the physical environment, it is important to provide information about dementia. This applies to people who have already received a diagnosis, to people who are concerned, to informal caregivers, but also to the general population so that they can learn how to deal with people with dementia.

Examples of this are:

- **Info point dementia:** an information point for dementia provides information, advice and can refer. The intention is that this is a low-threshold place. As an example, we take the [dementia information points in Slovenia](#).
- **Training sessions** of staff, shopkeepers, ...: This can be done by employees of the info point, walk-in house or by organisations that are committed to this.
- **Meeting Centers ([Meetingdem](#)):** This is a concept developed in the Netherlands and focuses on people with dementia living at home and their family caregivers. In the meeting centre there is room for social and recreational activities, information meetings, discussion groups, an individual consultation hour and center meetings. A good example inspired by this concept is the [Mente Locale Center](#) (AIMA Biëlla Italy). People with a diagnosis of dementia, family caregivers and people who do not have a diagnosis but still want to keep their brain (and body and soul) in good health are all welcome there.
- **Television and Media:** Informative but also recreational programs can help make dementia known and thus reduce stigma and create more openness for people with dementia in society. A nice example of this is [Restaurant Of Mistaken Orders](#) opened in Japan in 2018.

2.3. Meaningful Time Use

For people with dementia, it is very important to have a meaningful use of time so that they can feel useful and valued. With the right support, they can still add value to society. Providing familiar activities is important, but people with dementia can still learn new things and get satisfaction from them.

Examples of these are:

- [Dementalent](#): DemenTalent is an innovative form of service in which people with dementia continue to actively participate as volunteers in meaningful volunteer activities in society, in line with their talents, interests and abilities and facilitated and supported where needed.
- **Buddy organizations** : together with volunteers/ buddies, people with dementia can do activities individually or in groups. [Het Ventiel](#) (a buddy organization for people with young onset dementia) in Belgium is a good example of this.

- In addition, existing organizations (elderly organizations, libraries, sports clubs...) can become dementia-inclusive. With support and training, the organization or certain activities can be opened up to people with dementia.

2.4. Informal Care Support

When a person develops dementia, this directly affects the life of the family and informal caregivers. Supporting the network/environment of the person with dementia is crucial.

Caring for informal caregivers is an important task for care providers and policy makers. In order to ensure that informal caregivers are able to continue their work, there are a number of issues to be considered:

- Ensuring the health of the informal caregiver
- Preventing loneliness
- Providing a sufficient range of support services
- Navigating the care landscape and sharing information and providing training
- Increase the support capacity and resilience

Investing in care for family caregivers, so that they can keep up their duties, will ensure a lesser cost to society is and a greater involvement of citizens.

The WHO developed an [iSupport for dementia](#). This is a training and support manual for carers of people with dementia.

Examples are:

- [Talk cafe dementia](#) focuses on sharing expert information. This is to inform and support people coming into contact with dementia. In addition to the expert information, it is also a place where people can meet in an informal way. By sharing experiences, tips, feelings and stories with others, they can feel supported.
- Unlike the talk cafes, the [family groups](#) organized by volunteers from the Alzheimerliga Vlaanderen are aimed at contact with fellow sufferers.
- In Flanders, the Alzheimer's League has a free [listening and information line](#) from 9 am to 9 pm, also on weekends and public holidays. This information line is staffed by trained volunteers. They offer a listening ear, give advice and refer if necessary.

2.5. Technology

Assistive technology is technology that helps a person to engage in activities or participate in society, despite that person's limitations due to a disorder. Technology can support both individuals with dementia and family caregivers to make life more enjoyable. Domotics, lifestyle monitoring, location trackers, care robots, dementia-friendly communication technologies are examples of technologies that can be used to support the independence and quality of life of the person with dementia and his/her caregiver.



To know more

- Using technology to help with everyday life,
- Technologie en dementie

2.6. Prevention

If we compare the prevalence figures and the various modifiable risk factors of dementia, we can say that prevention is important. According to [the Lancet Commission on Dementia Prevention, Intervention and Care](#), 40% of dementias are preventable. Each percent gain means a lot in the organization of healthcare costs and the deployment of informal caregivers/care staff.

A prevention policy can focus on different areas:

- Adaptations to the environment so that a healthy life is possible and promoted. This includes access to education, primary care, healthy food and a healthy environment.
- Preventive measures: e.g. smoking avoidance, hearing loss policies, reducing air pollution, protective programs for traumatic brain injury.
- Training health professionals about dementia and its risk factors contributes to increased awareness, prevention, treatment and care

General and/or specific prevention campaigns can contribute to knowledge about dementia and the risk factors and the possibilities to reduce the incidence of dementia. E.g. Reduce the risk of dementia: [SaniMemorix](#)

2.7. Dementia Specific support

A case manager is an independent and permanent counsellor for people with dementia and their loved ones. Ideally, the case manager works closely with the geriatric specialist and the general practitioner through a multidisciplinary meeting. A case manager informs, guides, thinks along, advises and arranges care. In this way, the case manager helps to deal with the illness and its consequences in daily life. A case manager will not take up physical care themselves but will map out the path together with the person with dementia and his network. The case manager has extensive knowledge of the social map and can, together with the people, see which help is appropriate at what time.

Chapter 3 - Coordinated actions on dementia

Responsible partner: Foundation Compassion Alzheimer Bulgaria (BG)

The chapter in brief: All measures adopted by countries to tackle dementia must be related to human rights standards and the principles deriving from the Universal Declaration of Human Rights

3.1 Coordinated and Human Rights Based Approach

The existing good practices on coordinated action on dementia are from countries that are more advanced in tackling this socially significant problem. Such measures ensure:

- Ways to improve the lives of people with dementia, provide early diagnosis, facilitate access to treatment
- Good information on community and other types of support, broad public campaigns
- Effective links between care flows, public awareness, research and the fight against stigma
- Protection of the human rights of people living with dementia and their families and caregivers

These topics are present in the relevant strategies and national plans, adopted of the countries around the world and in Europe. Most of the programmes/national plans around the world are financially secured and include funds for research and participation of civil and patient organisations in the fight against the problem.

Countries that have made progress in fighting the disease also manage to propose measures and programmes for families, carers and carers for people with dementia. These range from different psychological support programs to help groups, training and counselling for dealing with stress and depression, etc.

Due to the lack of treatment, the guidelines for addressing the problem and the main objectives of caring for a person with dementia, according to the WHO, are as follows:

- Access to early diagnosis to ensure optimal management of the disease-related situation
- Optimising the physical health, cognitive functions and well-being of the individual
- Detection and treatment of challenges related to behavior and psychological symptoms
- Informing and providing long-term support to caregivers

WHO argues that people living with dementia must be provided with a human rights approach as very often their rights and those of their loved ones are violated. The Organisation urges the countries of the world and relevant organisations and institutions involved to strengthen their obligations to protect these rights. Moreover, the paradigm should be aimed at ensuring the participation of those affected by the disease in public life and in policies and decisions affecting them, as well as access to good quality of life and, respectively, to water, clothing, education, health, public buildings, transport, information and communication.

For more information see the [MYH4D MOOC](#).

3.2 Examples of Comprehensive Policies

The Global action plan on the public health response to dementia 2017–2025 of the World Health Organization contains ambitious targets for achievements at global level. Each Member State can be guided by these global targets when setting its own national targets, taking into account national circumstances. Each Member State will also decide how these global targets should be adapted for national planning, processes (including data collection systems), policies and strategies. Although there are specific challenges in each country in implementing these action areas, the Plan suggests a range of proposed actions that each Member State will need to adapt to the national context



Figure 1: Action areas of the Global action plan on the public health response to dementia 2017–2025.

A model of a National plan for action may contain the following basic elements:

- Framework for action: vision, objectives, principles and priorities for action. developing the national framework for action on dementia
- Key priority areas such as: care and support, access and equity, information and education, research, workforce and training.

In terms of policy, **people with dementia should be involved**. The benefits are that the voice will be heard and their expertise will be valued. This way the adopted policies will respond to their needs.

Alzheimer's Disease International (ADI) supports the creation of high-level plans to deal with the large and growing impact of dementia worldwide. 48 countries and territories have adopted a plan on dementia, including 39 WHO Member States. More information can be found on the [ADI web site](#).

3.3 Recommendations to Policy-Makers

There is a need for public policies and actions aimed to improved living conditions, safeguarding the rights of people living with dementia and their empowerment. Therefore, **close collaboration among different agencies is needed to make these actions effective and accessible and to contribute to the principle of active ageing and social inclusion. Government agencies, local authorities, educational institutions and civil society organisations have to work in cooperation to implement such comprehensive policies. The coordinated action means:**

- Making dementia a priority and adopting national and local policies, taking into consideration the 7 action areas of the Global action plan on the public health response to dementia 2017–2025. Provision of measures for improving the lives of people with dementia, access to early diagnosis, facilitated access to treatment.
- Developing specific strategies with the participation of the target group and encouraging actions at national level. Ensure their financial implementation and sustainability. Education and qualification of the service providers and care settings.
- Implementing nationwide information and awareness raising campaigns, engaging all stakeholders as well as other actors capable of impacting the sector indirectly.
- Implementing the campaigns at all levels and using the media and new technologies to attract all generations. Promotion of the rights of people living with dementia, with a particular focus on the ethical dimension of dementia in order to ensure healthy ageing in dignity.
- To use of the potential of eHealth and assistive technologies in improving support and care for people living with dementia
- Financial support of the NGOs and organisations that provide services for people living with dementia.
- The need to promote the role and continuing education of health professionals to ensure the best possible support for people living with dementia and their families.
- The promotion of dementia-friendly communities.
- Monitoring the implementation of the adopted legislation, policies, measures, actions also by dialogue and consultation with the target groups.

3.4 References

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Conclusion

Responsible partner: Foundation Compassion Alzheimer Bulgaria (BG)

The chapter in brief: All measures adopted by countries to tackle dementia must be related to human rights standards and the principles deriving from the Universal Declaration of Human Rights. Policy makers are recommended to follow good practices as standards for national and local level policies.

Coordinated policies are important for building greater social inclusion of people living with dementia. Ageing and dementia policies should be regarded as challenges and opportunities for fulfillment of the human rights-based approach.

The goals of the Global action plan on the public health response to dementia 2017–2025 and the respective the National plans/strategies of the countries on the globe require close collaboration among different agencies. The role of adult education and of the increased health literacy on dementia are among the key factors. Other essential efforts are:

- At a national and local level, **policy makers have a key role to play in order to promote learning opportunities for older people and make them more accessible for everyone.** Adult education has the potential to contribute positively to the development of key skills and competences, and to counter inequalities, but all relevant stakeholders need to keep those principles and guidelines in mind when designing or delivering adult education training, in order to ensure maximum learner engagement and motivation.
- **Improved health literacy** about dementia is very important to empower people and design policies to improve knowledge and competences about dementia. Health literacy on dementia could be the first step in achieving the goals cited in the National Dementia Plans or Strategies of different European countries.
- **National policies concerning dementia** and legislation with the aim to improve lives of people with dementia are essential. In terms of policy, **people with dementia should be involved.**
- **Integrated approach.** Integrated Care Approach means moving away from episodic care to a more **holistic approach to health**, care and support needs, that puts the needs and experience of people at the centre of how services are organised and delivered. Ideally, **this approach is person-centred.** Person-centred care involves tailoring person caring to their interests, abilities, history and personality.
- Creating a dementia-friendly environment consists of involving people with dementia in society. By giving dementia more visibility and by providing training for e.g. municipal staff, shopkeepers the stigma around dementia will reduce and people with dementia will feel valued.

The following recommendations support coordinated actions on dementia addresses the need for comprehensive policies that include:

Recommendation 1: increasing health literacy about dementia

- Implementing nationwide information and awareness raising campaigns, engaging all stakeholders as well as other actors capable of impacting the sector indirectly. Education and qualification of the service providers and care settings.
- Provision of measures for improving the lives of people with dementia, access to early diagnosis, facilitated access to treatment.
- Effective links between care flows, public awareness, research and the fight against stigma; protection of the human rights of people living with dementia and their families and caregivers.

Recommendation 2: developing integrative policies

- Making dementia a priority and adopting national and local policies, taking into consideration the 7 action areas of the Global action plan on the public health response to dementia 2017–2025.

Recommendation 3: developing coordinated and participative policies

- Developing specific strategies with the participation of the target group and encouraging actions at national level. Ensure their financial implementation and sustainability.

A call to action for policy makers:

It's a gist for those at the forefront of policy implement efforts toward educating the public, implementing better care practices for dignified life for people living with dementia and support national and local actions and policies through sustainable funding mechanisms.

Afterword 1 - Ethical Introduction

Responsible partner: Instituto Etica Clinica Francisco Valles (ES)

The chapter in brief: Four main ethical principles aimed at establishing normative boundaries for policymakers inspired MYH4D recommendations for policy makers: Harm principle, Least Restrictive or Coercive Means principle, Reciprocity principle transparency principle.

MYH4D recommendations suggest that policymakers intensify their effort to plan cost-effective strategies and promote sustainable and affordable policies to respond to and tackle dementia. In doing so, policy-making standards informed by evidence might encourage knowledge, skills and attitudes to build a culture challenging the stigma produced by dementia. Such culture might be inspired by general principles, wide-range societal values and a definite approach to promoting the participation and inclusion of people with dementia in decision-making about their health care.

Every public health intervention is improved when quality standards promote professionalism and build trust among citizens for health care professionals and services. Such a standard should be inspired by a core of ethical principles which strengthen public health and represent a benchmark for interventions.

To implement interventions related to people with dementia, we recommend four main ethical principles aimed at establishing normative boundaries for policymakers. The first one is named the *Harm Principle* and justifies the restriction of freedom only to prevent harm to others. Interventions involving people with dementia may reduce their freedom only when there is a risk to public safety and when their behaviour can cause harm to others. However, such restrictions should be imposed with the *Least Restrictive or Coercive Means* principle, aimed to limit the health authority's power when a measure is required to protect public health. For instance, limitation upon driving for a person with dementia is justified by the risk to others posed by the consequences of possible dangerous driving. This principle entails another crucial concern for policymakers implementing health policies, voiced by the *Reciprocity* principle. Society should facilitate individuals intended to owe their duties with appeals for public health. By way of example, burdens in terms of financial cost and time consumed produced by the care of people with dementia might be alleviated and recognised by society and public health authorities. Ultimately, the principle of *transparency* assures the inclusion of all stakeholders involved in decision-making processes and their information about deliberations affecting policies. Procedures must be explicit and responsible as possible, not influenced by conflicts of interest, and lacking political intrusions.

Promoting such principles requires a methodological strategy suitable for a democratic society whose healthcare services are organisations regulated by a culture of informed consent and shared decision-making. Deliberation is a procedure that assures rational and appropriate decision-making by analysing the circumstances and consequences of a choice and is a suitable tool for policymakers to design future policies tailored to societal needs and values.

A democratic society must join in the main choices about health and life and discuss them intersubjectively. Such enterprise should be embarked on foundational values established by political institutions and shared by citizens and community members. For instance, EU fundamental values such as human dignity, freedom, democracy, equality and human rights, and the Rule of Law agreed upon by member states.

Education in democracy has a deliberative character and spreads ethical principles and societal values, strengthening citizens' capacity for reasoning and enabling them to participate in policy-making. Promoting education and lifelong learning is a plan to spread deliberative culture and increase participation and societal awareness of dementia. Deliberation may improve literacy about dementia involving formal and informal caregivers, people with dementia and policy-makers to make decisions about issues caused by the illness.

To conclude, our recommendations for policy-making about dementia require the respect of an ethical framework suitable for public health interventions which interact with a democratic societal value system representing EU foundational values. The deliberative approach is a tool to spread such a culture of values and principles and promote as much as possible the inclusion of people with dementia in community decision-making.

Afterword 2 - MYH4D Methods

Responsible partner: Instituto Etica Clinica Francisco Valles (ES)

The chapter in brief: The consortium of Move your hands for Dementia (MYH4D) developed digital content following two main methodological approaches: Agile methodology and the capabilities approach. Both methods represented only a reference to advise the research team in developing the three intellectual outputs according to the needs of the target groups involved in our research activities.

A methodological note about MYH4D contents provided into the Intellectual Output (MOOC, Community of Practice and Recommendations).

The consortium of *Move your hands for Dementia* (MYH4D) developed digital content following two main methodological approaches: Agile methodology and the capabilities approach. Both methods represented only a reference to advise the research team in developing the three intellectual outputs according to the needs of the target groups involved in our research activities. The real-world focus of MYH4D aims to influence the work of trainers and informal carers through evidence-based practice. In doing this, we have structured our work into two phases: a generation phase inspired by the systematised review of scientific literature and qualitative research, which explored stakeholders' views with fifty in-depth interviews carried out in all the countries involved in the consortium. By the correlation between literature and individual experiences of dementia care, we have established a relationship between the circumstances of the illness and how they are experienced individually by people involved in formal and informal care. The strategy devised by researchers to design and develop the MYH4D's digital artefacts was assessed by a group of representatives of the target groups who assessed their feasibility during the entire course of the project. An evaluation phase located at the end of the production of each intellectual output estimated the quality of the single digital product. In the former, we ensured that all the designed contents were tailored to the learner's needs and in the latter, we explored how successful the artefact was perceived. The second methodological approach helped researchers to define a framework, whose clinical, social and ethical aspects were aligned and theoretically informed. The contingency faced by informal carers and the next-of-kin of people with dementia required an assessment of their welfare from a double perspective: the well-being achieved and the possible well-being achievable in the future. The British economist and philosopher Amartya Sen defined the former as something measured by functioning and capabilities. The progressive evolution of dementia demands a strategy to deal with present circumstances and plan a future passed by the deterioration of patients' quality of life. Martha Nussbaum, an American philosopher who owes Sen's theory a great inspiration, defined the capability approach as focused on "what people can be and do". That is why the capability approach represented a reference to the design of several of our MOOC's content and community of practice.

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