

For the Wellbeing and Dignity of Older people

European Quality Framework for long-term care services

Principles and guidelines for the wellbeing and dignity of older people in need of care and assistance

We have to go to bed at 6pm everyday and to stay in bed all day on weekends. They say they don't have enough staff to look after us.

I am afraid my daughters will decide suddenly to send me to a residential care home without talking about it to me beforehand. I like living alone and I would prefer to stay at home if possible.

My husband (79) has had dementia for two years. I called the Alzheimer helpline and I found what I am looking for: a long undisturbed conversation with a qualified person also giving me practical advice. This is so important for me!



I broke my leg two weeks ago but I continue to receive the same number of care hours as before. My son, who lives 100 km from my house, needs to come to help me every day to dress and to have a shower.

We mix everything together: first dish, main dish and dessert. We all know that older people lose their taste when they age, and we don't have time to spend to help them eat the three dishes one after the other. It is much easier like this.

The new head of unit made us realize that our workplace is home to older persons. We started putting emphasis on making life in our care home more 'homelike'.

Encouraging participation in daily life began with small changes. [...] The result was that we shifted from 70% to 20% of bedbound residents.

Let's join forces for the wellbeing and dignity of older people!



For the Wellbeing and Dignity of Older people

This publication was developed in the framework of the **WeDO project** by the **European Partnership for the Wellbeing and Dignity of Older people**.

WeDO is a European project (2010-2012) co-financed by the European Commission. It was led by a steering group composed of 18 partners from 12 European Union (EU) Member States interested in working together to improve the quality of life of older people in need of care and assistance. The project's aim was to set up **a lasting and open European partnership of European, national and regional/ local stakeholders committed to improving the quality of services for older people in need of care and assistance and to fight elder abuse.** The project ended in December 2012 with the launch of this European Quality Framework for long-term care services.

The WeDO project builds on the European Charter of the rights and responsibilities of older people in need of long-term care and assistance and its accompanying guide, developed by the EUSTACEA project (2008-2010, Daphne III Programme), and on the voluntary European Quality Framework for social services developed by the Social Protection Committee.

For the purpose of the project, a national coalition of stakeholders was set up in each partner country to identify the gaps, contribute to the writing of the Quality Framework and develop a national strategy to protect the dignity and wellbeing of older people in need of care and assistance through quality long-term care. Similarly a European coalition gathered key stakeholders at European Union level to help the Steering Group develop the European strategy.

Now that the project has ended, the European partnership is opening up to all interested parties from all EU Member States. We hope that more countries will join and develop new national and local coalitions.

More information, including examples of the implementation of the EU Quality Framework for long-term care services, is available on the WeDO project website: www.wedo-partnership.eu.

This is the EU edition of the EU Quality Framework for long-term care services.

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For more information and contact details: www.wedo-partnership.eu

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Terminology: what do we mean by...?

Active ageing: A concept which means "the process of optimizing opportunities for health, participation and security in order to enhance the quality of life as people age. Active ageing allows people to realize their potential for physical, social, and mental wellbeing throughout the life course and to participate in society, while providing them with adequate protection, security and care when they need them". (World Health Organisation)

Dignity: The equal and inherent value of every human being.

Elder abuse: A single or repeated act or lack of appropriate action which causes harm or distress to an older person or violates their human and civil rights. It may include physical abuse, psychological abuse, sexual abuse, financial exploitation and neglect. Elder abuse happens everywhere, including at home within the family, at home with services, or in care. It can be intentional or unintentional ('bad care').

Informal carers: Family, friends, neighbours and others who provide care to an older person in need of assistance. They do not usually have a formal status and are usually unpaid.

Integrated care: A coherent set of methods and defined processes to integrate care between hospital and primary care, health and social care, and formal and informal care. The aim of integrated care is to design and implement individual care pathways, financially and administratively coordinated with a view to achieving better outcomes in terms of effectiveness and user satisfaction. The provision of appropriate care at the right moment in the most appropriate setting implies collaboration in multi-disciplinary teams with the older person in need of care and assistance and their carers. When such structure exists, it is the role of the case manager to improve this collaboration.

Long-term care services or 'services for older people in need of care and assistance': They need to encompass prevention, rehabilitation and enablement, cure and care, including end-of-life care. They combine health and social care for activities of daily living (ADL) such as eating, bathing, dressing, grooming, housekeeping, and leisure. They also cover the "instrumental activities of daily living (IADL)" such as managing one's finances, shopping, using the telephone, transportation, and in some countries other activities such as taking medication. They can be delivered in various settings spanning the continuum from the beneficiary's home to intermediate care and (semi-) residential facilities.

Participation: Active involvement of older people in need of care and assistance and supportive measures for it, e.g. providing transport to attend social activities or to exercise civic rights, or support of older people with cognitive impairments. It should be supported until the end of life.

Professional carers: Home, community and residential care staff who receive payment for their work.

Quality: Degree or standard of excellence. Quality improvement in long-term care should be a continuous process by which a service or an activity aims at delivering better results through various means. These include a wide range of quality management tools and other mechanisms such as: training for carers, both informal and formal; support for users' fundamental rights; the promotion of an age-friendly and supportive environment including access to services; the definition of quality standards; and the assessment of results and outcomes by specific quality indicators.

Service providers: Public, non-profit and commercial agencies delivering services to older people in need of care and assistance in institutional, community or homecare settings.

Wellbeing: The condition of being contented, in the best possible health and integrated in society. Social interaction with family, friends and neighbours in the community and any relevant staff in long-stay settings can support the wellbeing of older people in need of care and assistance and improve their quality of life.

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Background

Why a European Quality Framework for long-term care services?

People are living longer. The number of older people in need of long-term care and assistance is increasing. Most of them are living at home and only a minority are cared for in a residential care facility. In many countries, care is mainly provided by informal carers.

In the last decade population ageing has become a key challenge for all EU Member States. It is even more so in today's context of budget constraint. Those aged 65 years or over will account for 29.5 % of the EU-27's population by 2060 (17.4 % in 2010). Public long-term care expenditure accounted for 1.2% of GDP in 2008 on average in OECD countries, and is expected to at least double and possibly triple by 2050. One of the key challenges for Europe is therefore to transform this longer life expectancy into longer active and healthy life years. It is also to ensure that our ageing population will receive the care and assistance they need to age in dignity and be protected from elder abuse.

In the last years the fight against elder abuse and the improvement of the life and care quality of older people have gained importance at international and European level with the support of several EU Presidencies, the European Parliament and the European Commission. The WeDO project builds on this momentum and takes due account of : the Charter of Fundamental Rights of the European Union and in particular Article 25; the United Nations Convention of the Rights of Persons with Disabilities; the General Recommendation 27 on older women and the protection of their human rights adopted by CEDAW in October 2010; the United Nations Madrid Action Plan on Ageing and the outcome of key European funded projects, as well as existing instruments and crucial work done in this area at national and local level in some Member States.

With this rapid growth of long-term care demands at home or elsewhere, an increasing number of stakeholders are involved in the provision of such services. This European Quality Framework on long-term care services is aimed at all stakeholder who would like to improve the quality of life of older people in need of care and assistance and contribute to more efficient long-term care systems, i.e. policy makers, care service providers, carers, older people's organisations, etc. It seeks to:

- Ensure a **common analysis and vision** on long-term care and raise awareness of the need to fight elder abuse and improve the quality of life of older people in need of care and assistance;
- Increase the participation of older people in the identification of their needs and the health and social care services they require, in quality development measures and innovation processes;
- Help to **develop fair and sustainable solutions** to improve the wellbeing and dignity of older people in need of care and assistance by facilitating the exchange of good practices within a country and cross border;
- Promote **better coordination and exchange of information** between the different stakeholders to improve the quality and efficiency of the services, and especially between policy makers, service providers and care professionals, and between the professional and the informal carers;
- Improve the quality of long-term care systems by reaching a good balance between efficiency, cost saving and quality improvement;
- Through these actions, improve the quality of life of older people in need of care and assistance.

How can the European Quality Framework for longterm care be useful for you?

This framework is an invitation to all relevant stakeholders at all levels (EU, national, regional and local) to build on what already exists in their country and to improve their system, getting inspiration from each other. Our aim is to encourage:

- **Policy makers** to create the conditions for the implementation of the European Quality Framework to develop fair, sustainable and efficient long-term care systems and services; identify good practices and consult systematically with other stakeholders such as older people's organisations and carers' organisations;
- Service providers (residential care homes, home care and community services for older people, etc.) to consult
 systematically all relevant stakeholders, including older people's organisations and carers' organisations, to
 assess their activities; base their internal quality management system on the WeDO quality principles and areas
 of action, organise training programmes for their staff around the Quality Framework, look for good practices.
- **Professional carers** to use the Quality Framework as a basis to discuss quality care with their colleagues, managers and older persons in need of care and assistance and their informal carers as well as any other relevant stakeholder, assess the gaps and reflect together on solutions to overcome them.
- Older people's and informal carers' organisations to use this Quality Framework to raise awareness of the need to improve the quality of life of older people in need of care and assistance and their carers and to fight elder abuse, to start/increase networking on this issue, and to communicate the needs and expectations of older people, professional and informal carers

The implementation of this quality framework requires a strong partnership and participatory approach where all relevant stakeholders (policy makers, service providers, funders, researchers, older people's organisations, informal carers, volunteers, industry, trade unions, etc.) work together to deliver quality care. These solutions have to include the views of the concerned older persons and to promote their dignity and right to be protected from abuse and neglect. For examples of how the EU Quality Framework for long-term care services can be implemented, please visit the WeDO website: www.wedo-partnership.eu.

Our analysis

There is a great diversity in the provision of care services across the EU, but everywhere eldercare models are changing rapidly. There is a general trend to postpone institutionalisation and keep older people at home for as long as possible in order to improve their quality of life and reduce long-term care costs.

Across the EU older people face the same problems regarding their need for care and assistance. Examples of the common concerns faced by older people across the EU are numerous: lack of support for informal carers who are often older people themselves; inadequate training and poor working conditions for professional carers; lack of specific structures for people with dementia; the negative image of ageing and of older people in society, the taboo about elder abuse; the difficulty in finding integrated care systems that are flexible enough to adapt to the changing needs of the person and that support participation and empowerment, etc. Different solutions and options have been explored to tackle these problems and a lot can be learned from each other's experience.

There is also an **increasing concern within public authorities to improve the cost efficiency of public services** in particular health, social and long-term care services. In today's context, in some countries it is increasingly difficult for older people to access affordable quality care especially when budget cuts are imposed without improving the care system's quality and efficiency.

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Older people suffer from ageism and sexism and from negative stereotypes linked to the fear of the ageing process. Consequently elder care is largely undervalued by society. The undervaluing of this sector poses particular challenges to female carers who comprise the majority of workers in the sector. Finally, the fact that women are overrepresented among very old people suffering from dementia and in need for long-term care can make this worse.

As demonstrated by a large body of research over the last decade, **elder abuse is a problem in all EU Member States**. It is found in all types of care settings (institutional, community and home care) provided by public, notfor-profit and commercial service providers as well as families and volunteers. In its call for proposals that funded the WeDO project, the European Commission explained that: *"Elder abuse in institutional and domestic settings is increasingly being recognised as a major societal problem. There is a risk that this problem will grow as Member States experience rapidly ageing populations. It appears, however, that only in a minority of cases the abuse of older people does represent a deliberate attempt to harm or exploit the victims."*

Our vision

The European Partnership for the wellbeing and dignity of older people (called hereafter the Partnership) promotes the idea that older people, just like any other age group, have the right to age in dignity and to be respected as full members of our society. The Partnership shares the vision that **more can and needs to be done to improve the quality and cost efficiency of services for older people and their carers through better care and assistance services.**

Ensuring high quality and dignity in care should contribute to improving the quality of life for all older people receiving care and assistance and to preventing elder abuse. We can and need to develop care models that are socially and financially sustainable in the long term and fair to all generations and social groups. All relevant stakeholders i.e. public authorities, service providers, older people's and carers' organisations, funders, need to be responsive, proactive, and innovative. They need to be aware of existing practices which offer older people high quality social and long-term care services while improving their cost efficiency.

Common values of the European Partnership

1. The Partnership calls for a rights-based approach to care as stated in the European Charter for the rights and responsibilities of older people in need of care and assistance, and the right to age in dignity until the end of life

"Human dignity is inviolable. Age and dependency cannot be the grounds for restrictions on any inalienable human right and civil liberty acknowledged by international standards and embedded in democratic constitutions." (European Charter of the rights and responsibilities of older people in need of care and assistance).

Older people, in particular those with complex needs such as people with cognitive impairments or with reduced mobility are exposed to higher risks of neglect and abuse, social exclusion and isolation.

Promoting a rights-based approach means for example fighting age discrimination, protecting service users' rights, ensuring access to reliable and comprehensive information, promoting a more accessible environment, and support for mobility, communication, consultation and participation. It also means implementing the concept of inclusion as promoted in the UN convention on the rights of persons with disabilities. It can be realised for example through supporting the development of personal social networks, a supportive neighbourhood, civic support systems, involvement of older people in the organisation of local participatory planning, etc. Specific attention has to be paid to protect the rights of older people with cognitive diseases within the social and legal context. These may impact on their right to self-determination or allow limits to the person's right to free movement.

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2. The Partnership wants to see age-friendly environments and active ageing as key concepts to drive the evolution of long-term care systems

Older people in need of care and assistance are not valued enough and included as full members of the society. The Partnership calls for a shift in the way our societies are organised and a change in the way older people and ageing in general are perceived. Building on the concepts of active ageing and age-friendly environments, the Partnership stresses that everything should be done to enable the person to live autonomously for as long as possible. Older people in need of care and assistance must be involved and empowered to define how their needs, expectations and preferences can be met.

3. An integrated response to care and assistance needs is considered by the Partnership to be the best way to ensure that care delivery is optimised and adapted to the needs of the users and their carers

An integrated response to care and assistance needs covers very different types of care: all healthcare; social services targeting older people in need of care and assistance; care for cognitive diseases; palliative and end-of-life care; services delivered at home, in the community or in a residential care home; public or private-funded; and informal care or care by volunteers. For all these services, the Partnership considers that it should be a priority to develop a 'person-centred' approach, i.e. that the dignity, participation and empowerment of the older person in need of care and assistance are supported.

4. The Partnership acknowledges the crucial role of informal carers and believes that measures to improve the quality of long-term care must cover support for informal carers, particularly recognizing that they need time for respite

Informal carers provide the bulk of care to older people in need of care and assistance (depending on the countries 70 to 90% of care needs are covered by informal carers). Informal carers, many of whom are family members, women aged 55 and over, provide a high amount of the care work, many of them as a support for their beloved relative. They are nevertheless a particularly vulnerable group and are at a high risk of burn out, abuse and/or social exclusion.

The quality of life of the informal carer is closely linked to the quality of life of the older person in need of care and assistance. Services therefore have to consider support for informal carers as an integral part of the quality improvement process, as well as the need to improve cooperation between formal and informal care. The Partnership considers that family members should have the right to refuse to provide informal carer. Likewise older persons in need of care should have the right to refuse to receive care from informal carers. In some countries, the role of migrant care workers - including undeclared migrants - is a particular challenge that needs to be addressed through supportive measures.

Part 1: Quality principles and areas of action

The principles and action areas of the European Quality Framework for long-term care services are interlinked and must be pursued together through various means and by different stakeholders. Improving quality in a service has to be done together with a general improvement of the environment. The Partnership acknowledges that conflicting goals may arise. In such situation a balance needs to be found through dialogue between the stakeholders. The decision should always be taken in the best interest of the older persons in need of care and assistance and should seek to improve their wellbeing and dignity. Examples of good practices mentioned in each chapter can be found from p.38 onward.

Quality principles A quality service should be:

Respectful of human rights and dignity

Services for older people in need of care and assistance, and public authorities responsible for them, should respect the fundamental rights and freedoms of older people, their families and carers as outlined in national, European and international human rights instruments.

Losing one's autonomy can be very traumatic. It requires a humane approach that protects the dignity of the older person until the very end of life.

What does it mean?

- The rights of older people are the same as for any other age group.
- → A service has to respect the human dignity of the older person, and should be provided without discrimination based on age, race, colour, national or social origin, financial means, beliefs, sex, sexual orientation or identity or degree of care and assistance required.

Case example: Austria

One of our residents was unable to speak to us about his wishes. His voice was his wife who visited him every day. One morning the situation of this old man was very bad. We were sure, that he would die within the next hours. We informed his wife who insisted on hospitalization for her husband although a doctor told her that her husband's condition was so bad that he probably would not survive the transport. When a nurse asked her how her husband would decide she became very angry and told us that he could not decide and she wanted hospitalization. Some minutes after, the paramedics came back to tell us that

our resident had died in front of the nursing home in the ambulance. The wife was then uncertain whether she had made the right decision.

In Austria, 80% of nursing home residents are suffering from dementia. Many of them are not able anymore to verbalize their wishes. **The Ethical residents' conference** is a process which involves all relevant stakeholders to discuss these issues with the resident. At the start of an ethical conference the situation is described. The participants discuss alternatives and their positive and negative consequences. They listen to the resident's wishes and needs, and members of the family are involved. The decision made after a discussion is an understanding about what is good in this special situation and usually a palliative sheet is written. This gives employees more certainty in the implementation of ethical decisions. Decisions are to be considered as preliminary and to be verified with every new question. Link for more information: bit.ly/Mf7HP4

See good practices 15, 16, 24

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Person-centred

Services for older persons in need of care and assistance should address in a timely and flexible manner the changing needs of each individual, fully respecting his/her personal integrity with the aim of improving their quality of life as well as of ensuring equal opportunities in access to care. Each individual has her/his own character, interests, life history and family circumstances; and his/her own social and health needs, capacities, and preferences. These characteristics should form the basis for service planning, care management, staff development and quality monitoring.

Services should take into account the physical, intellectual, cultural and social perspectives of older persons, their families or others significant to them in their lives. In addition services should ensure that they give staff the necessary support, resources and facilities to work in this way. Person-centred services should be driven by the needs of the older persons and, when appropriate or as necessary, of their relatives or carers.

What does it mean?

- → Take into account and respect the free will and own life choices of the older person.
- → Take into account and respect the older person's ethical, religious and social background, beliefs and needs.
- Help and empower the person to express his or her wishes in all phases of their lives for the short and longer term.
- → If the person cannot take decisions for him or herself, the third party or advocate should seek to respect his or her fundamental rights, life choices and wishes.

Case example: Germany

Mrs. L. was part of a church choir where she had sung for many years. Due to her cognitive disease she was often restless and ran around the room during the waiting periods or asked which song was next during the performance. Soon, the other participants no longer wanted her to participate and she was forced to resign.

A well-trained volunteer could support Mrs. L. and provide her personal assistance to allow her to continue to participate in the choir. This volunteer could compensate and support her during rehearsal and mediate between her and the other members of the choir and thus strengthen the civil rights of people with dementia. Since the reform of the **German Long-Term-Care Act** in 2008 (SGB XI) older people "with limited life skills" - the majority with cognitive diseases

– can claim up to 2,400 € per year for low-threshold assistance or supervision and support in groups or at home. Meanwhile organizational structures have been established nationwide to train and place these voluntary low-threshold "everyday companions" (Alltagsbegleiter). Due to the latest reform of the Long-Term-Care Act in 2012 the support for people with dementia (both in kind and in cash) will increase from 2013 onwards.



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Preventive and rehabilitative

Services for older people in need of care and assistance should seek to prevent deterioration in – and to restore as far as possible – the older person's health, wellbeing and capacity to live independently. Empowering older people in need of care and assistance to regain the ability or find new ways of coping with their limitations helps them remain in charge of their own life.

What does it mean?

- Support autonomy as much as possible, including through home adaptation, use of assistive devices or rehabilitation nursing.
- → Early health promotion and prevention of age related diseases.
- \rightarrow Prevention of social isolation.
- → Focus on the person's health and abilities, not on his or her illness or incapacities.

Case example: Finland

"We unfortunately 'preferred' incontinent to continent people, as the workload was lower with the use of diapers. So even if the persons were continent, we sometimes used diapers, and over time they became incontinent." A former care home nurse

"We have noticed that there is an increase in the number of incontinent residents in our nursing home. At the same time urinary infections have become more common causing discomfort and affecting the quality of life of these old people. I think these two problems are connected. And I also think that it is not humane to make

grown-up people use diapers! Something should be done, but I don't know what and how." A nurse

Incontinence affects greatly the quality of life, and the proportion of continent residents is therefore a good criterion for the quality of care. In 2010 **a project to improve residents' bladder continence** was set up in a nursing home in Finland. Nurses were first given a course on toileting programmes. An intervention group of 71 to 94-year-old residents was selected on the basis of their cognitive skills and physical status to involve those who would most likely benefit from the toileting programme. Assessments were done using a multi-disciplinary quality tool called Resident Assessment Instrument (RAI, www.interrai.org).

Initial states of incontinence were described and recorded. Individual goals and means were set relative to each person's situation. Individual schedules were made to ensure the person would regularly go or be helped to the toilet. Residents were motivated, reminded, and/or helped. Bedpans or urinary bottles were used during the night if needed. Toilets were made easily recognizable.

Reassessments showed that continence of 16 of 24 people was improved during the 5 month intervention. Many learned to go to toilet on their own or were motivated to ask help when necessary. 19 people could use lighter incontinence pads or briefs, 3 showed improved bladder continence, 9 improved bowel continence and 4 people both improved bladder and bowel continence. One important benefit was a lower occurrence of urinary infections. Savings in the costs of incontinence pads were approximately 4000 € per year. This project showed that finding and supporting remaining competences of even very old people is worthwhile. Weblink: bit.ly/NmrI3E

See good practices 1, 7, 23, 27

Available

Access to a wide range of services should be offered so as to provide older people in need of care and assistance with an appropriate response to their needs. Services should be available as a support to independent and self-determined living as well as offering freedom of choice within the community whenever possible. They should be set in a location which is most beneficial to the older person, their families and carers.

Public authorities should ensure that services for older people have sufficient capacity, geographical coverage and professional range to be able to preserve and improve their health, wellbeing and independence.

The availability of services can be ensured by strategic planning (involving potential users), funding and organisation of services by public authorities with the support of service providers, to provide an adequate answer to the needs of older people.

What does it mean?

- A service exists to answer each need for care and assistance.
- The older person has a choice among different options.
- → There are no long waiting lists.
- There is adequate funding to enable free choice.

Case example: Greece

"My father suffers from Alzheimer's. Although we take care of him, he often gets lost. To find him we used to ask the neighbours, call the relatives or put up some posters in busy roads and points of the area, always hoping and wishing that someone would inform us that they had seen him. In one of these cases my father was found after three days, in a very bad condition, in a park far away from our house. The doctors said that it was a miracle he managed to survive the hunger and the cold. A month ago my father got lost once again. Then a friend of mine talked to me

about Silver Alert. In a few hours a whole process was activated, television channels, airports, the subway stations announced Silver Alert for my father. I felt that the entire world was looking with me to find my father. My father was found sound and well by a bus driver who had seen the Silver Alert announcement on the television. I really think that Silver Alert is a solidarity initiative, a project which can be very useful for people like my father."

Life Line Hellas in cooperation with **7 public bodies** (the ministry of citizens' protection, the ministry of justice and human rights, the ministry of public transportation, the ministry of health, the Supreme Court, the local police) and with the cooperation of **6 radio and tv stations** have been working on the Project **Silver Alert** which has as prior goal to help people that get lost primarily because of Alzheimer's disease, to get traced as soon as possible. A photo together with basic information is posted for 30 seconds on TV, Radio, digital screens on train, metro stations and the airport. In this way a lot of people get found very early and return to their families.

The Project is being funded by the Niarchos Foundation for a year. Because of its success the national WeDO coalition has raised its importance and will support its growth through seminars to the police academy, the hospital staff etc. Also a cooperation with the Association of Greek Residential Homes is about to start in order to be able to provide care for a few days for the people found wondering around on the streets (but not reported, thus a Reverse Silver Alert) until their family or a more permanent home is arranged for them. www.lifelinehellas.gr

See good practice 3, 4, 18

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Accessible

Services for older people in need of care and assistance should be easy to access by all those who may require them. Information and impartial advice about the range of available services and providers should be easily accessible to older people themselves and to their families and informal carers. People with disabilities should have access to the service, to adequate and affordable transport from and to the service, as well as to adapted information and communication (including information and communication technologies).

What does it mean?

- → The service or information respects the 'Principles of Universal Design', i.e. the concept of designing all products and the built environment to be usable to the greatest extent possible by everyone, regardless of their age, ability, or status in life.
- → Communication is simple, easy to read by all.
- → When the person cannot access the service, the service comes to the person or its access is facilitated by an intermediary service.

Case example: Netherlands

Mrs. T. is 83 years old. She is a kidney patient and as a volunteer she teaches migrant women Dutch in another town. "I always travelled by public transport but, now that I have to go to the hospital twice a week for dialysis, I noticed that my energy level is very low. Travelling by public transport with changing trains and buses is too tiring for me. I cannot walk very far any more. But I really would like to continue with the lessons. It gives me a lot of pleasure and satisfaction. Moreover, I feel I can still contribute to society".

With the **complementary transport services** Mrs. T. can keep on volunteering and doing most of the things

she used to do. There are several services in the Netherlands for people who are not able to use public transport. To access the necessary care services special transport services are covered by health insurance when one has a chronic illness. For social contacts, attending activities or going to the doctor, shopping, etc. there are transport services paid by the municipality and the national government. One has to apply for these services and meet the criteria. People get a maximum amount of kilometres per year, and transport has to be booked in advance and is often shared with other people.

See good practices 7, 18, 21, 23, 26

Affordable

Services for older people in need of care and assistance should be provided either free of charge or at a price which is affordable to the individual without undue compromise to their quality of life, dignity and freedom of choice (the concept of universal access).

What does it mean?

- Access to the essential services the older person needs is not dependent on their financial resources.
- → The service is free of charge or if not, the person can benefit from a wide range of financial or in-kind support that contributes to help to cover as much as possible the cost of the service.

Case example: Italy

A municipality in Italy has among its population over 2,000 people with disabilities or not able to live independently. Among them, 70% have a low income and would not be able to purchase the services they need to be supported in everyday life.

In 2004 Emilia Romagna Region introduced the so called **"Regional Fund for Dependency".** The fund is provided by surtax on IRPEF (the national tax of incomes of physical people). In 2011 the yearly amount available was of about

480,000,000 € (30,000,000 € directly from the dedicated taxation and the rest from the Regional budget).

The fund targets older and younger people with disabilities and is managed at local level, according to regional guidelines developed by health and social care authorities together with representatives of NGOs and trade unions.

The fund finances a variety of services mainly aimed to support home care of people with disabilities (i.e. care allowances, home care services, training of home care workers...). A part of it is dedicated to reduce the costs to users of residential care services (such as nursing homes).

See good practice 14

1 NeDO

Comprehensive

Services for older people in need of care and assistance should be designed and delivered in an integrated manner which reflects the multiple needs, capacities and preferences of the older person and, when appropriate, their families and carers, and which aims to improve their wellbeing.

What does it mean?

- ➔ An older person in need of care and assistance has very diverse needs and expectations.
- → The service takes this complexity into account in its work and answers to the different needs in as far as possible. The service therefore looks for a partnership approach within and between the organisations working with the older person
- The care is organised around the person and minimizes the efforts required from the older person to find an adequate service to answer his/her needs.
- → A comprehensive approach by the service should be supported by an adequate regulatory framework, organisational visions and missions, and professional approaches to long-term care.

Case example: France

Mrs. D. is 79 years old and she has Alzheimer's. She lives at home and her husband takes care of her. He benefited recently from home care services which help him with grooming. But the situation of Mrs. D. is worsening, mainly because of lack of stimulation. She begins to undress in the middle of the day; she does not recognize her husband anymore. It is impossible to understand what she says.

Mr. D. is exhausted. He feels depressed not to be able any more to communicate with his wife with whom he has been sharing his daily life for 50 years. He is in a situation of 'burn out' and professional carers from the home care services are worried about him.

The Gironde **public local network of help at home** gathers the local network of social services of the Gironde province and 34 other public stakeholders. Thanks to the existence of a **legal status called 'Social and medical stakeholders cooperation group'**, this local network could be created. It ensures that a community-based and quality public service is maintained for frail people and

simplifies the administrative and financial management of the support provided. This system prevented the cut in funding for frail people while guaranteeing a quality service on a large geographical scale (164 cities covered). It also helps to apply a holistic approach while acting locally, in respect of the needs of care recipients. For example, this local network launched a study on the needs of older people in need of care and their carers in cooperation with the University laboratory on cognitive sciences. Priorities were defined after discussion among the university, the older people themselves, the carers and the funders. The cooperation will lead to the development of ICT-based services used for people like Mrs. D. to stimulate their mental capacities.

See good practices 2, 3, 16

Continuous

Services for older people in need of care and assistance should be organised so as to ensure continuity of service delivery as long as it is needed and, particularly when responding to long-term needs, according to a life-cycle approach. This enables older people to rely on a continuous, uninterrupted range of services, from early intervention, care and support, to palliative care, while not disrupting the service. Care providers should work together to facilitate transitions between different care services and settings as needs evolve.

What does it mean?

- → The service is reliable, delivered on time and flexible.
- The service is based on the person's changing needs and can be easily adapted to answer them over time.
- The person can ask one coordination service to cover all his/her diverse needs.
- A good coordination of services is put in place including when a person is admitted in a hospital or comes back home to ensure a proper transfer of information.
- → A continuous approach by the service should be supported by an adequate regulatory framework, organisational visions and missions, and professional approaches to long-term care.

Case example: Slovenia

Seven years ago Rok, already retired for several years, lost his wife. They had no children and his wife's death pushed him into isolation and depression, and at the end his health began to worsen. Seven years ago the first Daily Centre of Activities was opened and Rok was curious enough to try it. Rok is a shy person and he did not even try to speak with others. He joined the morning exercise group, first occasionally and then each morning. His physical condition soon improved (to the great surprise of his doctor). He started to talk of the pain that the death of his wife provoked and his feeling of acceptance was raised. He then joined other activities such as chorus, card playing, memory training and culinary courses. He is now running the morning exercise group and his cakes are known as 'Rok's cakes'. He found a kindred soul, and together they are picnicking, dancing and gardening. His social network is now well-grown and he is back in the active part of the life.

In the nineties, institutional care was in large extent the

only solution for older people in need of care and assistance. In 1999 the Ljubljana municipality consulted with the older people's organizations and decided to create **Daily activities centres**, a low-threshold advice point and a first step in the developing chain of uninterrupted range of services. Other steps were the creation of an Institute for home care as a subsided public service and other either public services or services in public-private partnership in Ljubljana and other parts of the country. In 2005 the first Daily Center of Activities (DCA) opened in Ljubljana.

There are now five DCAs and they are considered to be a success. With a membership fee of 7 euros per month, they are financed mainly by the municipality of Ljubljana and the Ministry of labour, family and social affairs. They each offer from 30 to 35 different activities per week. The participatory method was used to discover both the need to introduce this type of inclusion point and to better know which activities older people are interested in. Meanwhile, most institutional care homes are now offering daily care as well. In 2011 two new initiatives contributed to improve the chain of care and support with nursing hospital and palliative hospital. The pressure on institutional care seems to decrease; the possibilities for active ageing and inclusion are now accessible by every older citizen in Ljubljana.

See good practices 3, 4

Outcome oriented and evidence based

Services for older people in need of care and assistance should be focused primarily on the benefits for the older users. They should be oriented towards improvements in a person's health, wellbeing and independence, taking into account, when appropriate, the benefits for their families, informal carers and the community. Service delivery should be optimised on the basis of periodic evaluations and adhoc checks which should inter alia take into account feedback from users and stakeholders in order to improve service delivery and aim at excellence. These benefits should be based on the best available evidence of what leads to such improvements.

What does it mean?

- → The service monitors users' satisfaction and health/wellbeing and feeds this information back to set clear, agreed quality objectives and thus improve the quality of the service. The service is focused primarily on the benefits for the older people and cost efficiency is balanced against these benefits.
- → The service cooperates with the education sector, including universities.

Case example: Sweden

In the winter of 2011/2012 a debate on care for older people that had been quiet since the nurse Sarah Wägnert (Lex Sarah) 1997 went out and talked about how the old in a private nursing home in Stockholm were suffering, re-emerged. Then, the discussion was about whether Sweden would privatize long-term care at all. Now the debate in the media focused primarily on the profits made by private service providers and whether it is appropriate that a venture capital firm should run welfare services. The owners' profits were forcing savings that harmed patients, demonstrated by a wide range of examples.

Another problem was that the local authorities seemed to have lost control over the procurement procedures. These scandals in the media made a difference. The government proposed new legislation. But most importantly, the people responsible for both public and private long-term care services saw it was impossible to lower the quality of services, including for people with dementia who are unable to speak for themselves.

In 2012, the Ministry of Health instructed the SIS (Swedish Standards Institute) to develop **Swedish standards for quality in care for older people,** related to both public and private long-term care providers. The goal is higher quality of life for older people with greater needs, and the effective implementation of improved quality. The assignment includes developing new quality standards in nursing homes and in home care. The standards can be used for example by local authorities in the procurement of long-term care, or to benchmark quality.

The standards shall among other things be used to: clarify the responsibilities of service providers, help organizations to manage quality monitoring processes and activities, and provide a basis for internal improvement. Standards can provide clarity about what characterizes good quality long-term care in nursing homes or for people who need care at home. SIS intends to set up two task forces comprised of relevant stakeholders and experts to develop standards. A wide range of stakeholders is involved in the process (including older people's organisations, but also public and private stakeholders at all levels).

See good practices 6, 10, 15, 19, 24 and p. 31

Transparent

Services for older people in need of care and assistance should provide clear and comprehensive information and advice to users and potential users about the services they offer, their cost to the user, and how to access or cancel the service(s).

The information should be reliable, updated and available not only upon request but also through publicly accessible communication tools such as helplines, leaflets, websites, etc. Service users should be informed well in time about any change that will affect the service they receive and should be provided with information about alternative solutions if they so require. Outcomes of checks by controlling authorities and quality evaluations should also be posted on publicly accessible communication tools and be easily accessible to users at any time in accordance with the national legislation on the protection of personal data.

What does it mean?

- → The service provides full and accessible information on its activities and the cost charged to the user.
- → The service provides information on the reports of quality controls concerning the service.
- → The service is transparent on the decision making process on care.

Case example: Ireland

'Our 78 year old mother became ill very suddenly. She was not likely to get better, and it was obvious she would need nursing home care. As a family we knew nothing about residential care, and there seemed to be nowhere to turn for advice. We visited a few places, but found it hard to find somewhere with a vacancy that we felt was right for her. We had to accept a temporary solution which did not suit my mother. My mother did not stay there long, and we have found somewhere where my mother is very happy. Placing a loved parent in long-term care is usually

difficult. Working without support or information can increase the problem.' Irish daughter.

Choosing a nursing home can be difficult for families. They may have to make a speedy decision due to a crisis. They may be upset that a family member must leave home. They may know little about nursing homes and feel ill-equipped in assessing potential options.

Myhomefromhome.ie is an Irish website that helps families choose the nursing home that best suits their needs. The website lists private nursing homes in Ireland by name and location. It gives details on the services and facilities available in each so that families receive comparative information. The website also provides links to Health Information & Quality Authority (HIQA) reports, supplies funding information and advice on alternatives to nursing home care.

Myhomefromhome.ie is a service within the Third Age Advocacy Programme established in 2008 to provide an independent advocacy service for older people in residential care. For more information log on to www.myhomefromhome.ie and www.thirdageireland.ie

See good practices 8, 15, 22

Gender and culture sensitive

Service providers should pay due attention to gender and culture in care, i.e. to the specific needs of women and men and to cultural differences among both their staff and care recipients.

The concept of culturally sensitive care respects biographical, linguistic, cultural, religious, and sexual diversity of the person in need of care and their carers. It aims at: opening the care system for everyone; awareness raising of professional staff; providing health care and long-term care in the mother tongue of migrants or by using interpreters; and considering the gender specific aspects of care.

What does it mean?

- The service respects the right of staff and care recipients and makes reasonable accommodation for their cultural heritage, social background, religious values or practices.
- The service does not discriminate against anyone (i.e. fights against ageism, homophobia, sexism or racism).

Case examples: Netherlands and Germany

Mrs. S., an amiable older woman of 83 years old, lives in a home for older people in a big business-city in Holland. Mrs. S. is a sociable person who is sometimes afraid to show that she is a lesbian or to talk about her lesbian lifestyle. One day, she receives an anonymous note in her mailbox which says: "Go to your own people! We don't want you here in this house...!"

In The Netherlands, the **movement Pink 50+** undertakes lobbying and advocacy for older homosexual people (LGBT). They accomplish a lot of projects in their master

plan called: "Beyond invisibility". The **project 'Pink Pass Key**" is to help and stimulate residential care homes and care staff to act and think "gay-friendly". Management of these homes and organizations often do not realize the need of older LGBT's to live their lives as they were used to. Therefore Pink 50+ developed a tolerance-scan (see also: www.rozezorg.nl). After the first successful audit the home receives a certification of The Pink Pass Key. After this they have to do the audit 3 times every year. A web-based community (Pink50+) was also created (www.roze50plus.nl).

Mr. Ü. is a Turkish migrant in Berlin who has developed dementia a few years ago. He worked as a mechanic in the automobile industry and was quite fluent in German. Due to his Alzheimer's he cannot rely on his German anymore and needs to communicate in his mother tongue. Last year his wife died and his four children cannot look after him the whole day because they all work. They are looking for a care setting for their father where his culture, religion and habits can be respected and he can live his familiar life.

Older migrants are in many cases disadvantaged in accessing and making use of adequate health and social care services. In 2000, a working committee under the name of '**Charter for Culture-sensitive Care in Old Age'** was founded by social welfare organisations working with older people and migrants. In 2006, the working committee was transformed into a **Forum for culture-sensitive care in old age** with the involvement of national government representatives, national and local welfare associations and migrant organisations in Germany. The committee developed a memorandum, a support manual with innovative approaches and practical tools for the implementation of culture-sensitive care for older people, training courses, as well as networking, lobbying and public relations. www.kultursensible-altenhilfe.de

See good practice 20

Areas of action A quality service should also contribute to:

Preventing and fighting elder abuse and neglect

Services for older people in need of care and assistance and public authorities responsible for them should do their utmost to ensure that older people, their carers, family members and staff are free from abuse, harassment and neglect. Such measures should include the protection of victims and whistle blowers.

What does it mean?

- The service is informed, trained and prepared to raise awareness of, detect and fight elder abuse.
- A protocol is set up to allow users, families and staff to report elder abuse and neglect in a way that protects the victim and the person who reports abuse.
- → Different types of elder abuse need different types of interventions plans (financial, physical, psychological, etc.).

Case example: Belgium and Finland

When Paul, a man aged 76, needed to undergo a small surgical procedure, he gave as a precaution a power of attorney for his bank account to his children. When he returned home from the hospital, a large amount of the furniture had disappeared. The home nurse, who did the aftercare of Paul's surgery, noticed that there was not much furniture, but she did not know the condition of the house before. However, when she proposed to have meal deliveries, and a cleaning service to make Paul's life easier, he said he did not have the money for such expenses. Knowing that Paul had occupied a high position in the Post Office, she became suspicious. After she had insisted for some time, Paul admitted that his children took

complete control over his bank account and granted him a small monthly allowance. When the home nurse raised this issue with his children, they said an older person did not need more money, and that "otherwise he would spend it all".

Some months ago the home nurse followed a training course, organised by the Registration Centre for Elder Abuse. There they talked about the different types of elder abuse and how you can recognise it. She remembered some examples of financial abuse, and thought this could be the case for Paul's situation. Therefore, she decided to call the Centre and tell about this situation. They were very helpful and they arranged a meeting with the children and Paul to talk about the situation and to work out a solution for Paul.

In Belgium, the **helplines and registration centres for elder abuse** provide advice, counselling and intervention for people who experience or who have witnessed elder abuse. It aims at helping people in abusive situations. Additionally, they provide trainings and workshops for social and health services, and care organisations, on how to recognise and detect elder abuse. www.meldpuntouderenmishandeling.be (in Dutch), www.respectseniors.be (in French), www.home-info.be (Dutch and French), www.inforhomes-asbl.be (Dutch and French)

In Finland, Paul could contact the **Finnish Association of the Shelters for the Aged.** This organisation runs a weekly peer support group for older people who are or have been experiencing abuse. The group is guided by two professionals. Its aims are to raise awareness of different types of abuse, stop abuse and empower older people to control their own life. Each candidate member is interviewed for making sure she/he is able to join and work in the group. According to feedback from the members, the group has been beneficial for their life situation to stop abuse and improve their quality of life. suvantory.fi/en/.

See good practices 5, 11, 25, 28

NeDO

Empowering older people in need of care and create opportunities for participation

Services for older people in need of care and assistance and public authorities responsible for them should encourage the active involvement of the users, and, when appropriate, of their families or trusted people and of their informal carers in the planning, delivery and evaluation of services. The service provision should empower users to define their personal needs and to keep control of the care and assistance they receive. Public authorities should engage older people (not only those currently using services) in the planning and evaluation of care and assistance services, and also in local policy-making aiming to promote age-friendly communities.

What does it mean?

- → Services should facilitate social integration of older people receiving care.
- → The older person is best placed to define her/ his needs and what can help to improve his/ her wellbeing. The older person should have the right to take some risks and carers should respect that, within what is allowed by their national legislation.
- → The older person has opportunities to continue old hobbies and to participate in new ones including social, cultural, civic or religious activities if she/he wants to, outside or inside his/her home.
- → The person has full and accessible information on how the care system is organised, how the person can volunteer or be an active citizen, what are his/her legal rights.

Case example: Finland

"My mother who lives in a residential care home has Alzheimer's disease and is losing her ability to talk. She is a lovely old lady as long as familiar staff is taking care of her. New recruits and substitutes do not know her habits and wishes and that's when problems arise. Suddenly my sweet and happy mother became grumpy and "a difficult case". I wish there could still be some way my mother could have more influence on how her daily life is managed." Son of an 87-year old woman

Elo-D is a tool developed in 2005-2008 in a Finnish project to improve the wellbeing and quality of life of older people with cognitive disorder. Elo-D is based on the observation and information expressed by the older person. One of the goals is to improve interaction between the person and his/her carer. Using Elo-D it is possible to assess whether the care and services given fulfill a person's needs, helping to ensure good quality of life and psychosocial well-being. Elo-D gives measured information on feelings of comfort or malaise and social interaction. It also shows how much the care and service

culture supports the well-being of a person with cognitive disorder. By follow-up assessments it is possible to measure changes in the person's well-being. Elo-D is used in special care, long-term care, residential care and respite care units. A training programme for using Elo-D is available. www.muistiasiantuntijat.fi/page.php?page_id=95

See good practices 12, 13, 19 and p. 35-36

Ensuring good working conditions and working environment, and invest in human capital

Services for older people in need of care and assistance should be provided by skilled and competent workers with a decent salary and stable working conditions, and according to a manageable workload. Workers' rights should be respected and confidentiality, professional ethics and professional autonomy protected. Opportunities for continuous learning and improvement should be available to all care staff. Migrant carers, volunteers and informal carers should also be supported.

What does it mean?

- → The staff is adequately trained, including learning or upgrading geriatric and gerontological skills and is available in sufficient number to look after all users.
- → Staff has access to life-long learning and receives support to cope with difficult situations and challenging behaviours.
- The management values the work done by the staff and invests in improving their working conditions and supporting the reconciliation of work and family life.
- → Salaries reflect the responsibilities and workload of each staff member.
- Informal carers have the opportunity to receive adequate training and can have the skills they acquired through care work officially recognized.

Case example: Italy

Ms. L. is a 45-year-old Russian woman with a background in engineering. Since her arrival in Italy, three years ago, she has always been employed as private assistant by Mrs. R. When Mrs. R.'s health conditions got worse and she was moved to a nursing home, Ms. L. needed to find another job and turned to the care job offer and demand matching service managed by the local municipality. The officer told her that, in order to be inserted in the data base, she needed to prove her skills in the care sector, either providing a diploma or demonstrating that she had all the necessary competences.

Ms. L. would be interested in attending a course but she urgently needs to find another job – the officer suggested that she have her skills validated. If she demonstrates to have all those foreseen in the profile she will be inserted immediately in the data base. If not, she will be only requested to attend the training modules related with the skills she does not have, thus shortening the training course.

In Italy, an initiative was launched to find a way which

enables Ms. L. to validate her skills: **the Care Talents Project.** It was funded under the Lifelong Learning Programme Sectorial Programme Leonardo Da Vinci (2007-2010) - Action TOI. It is a transfer/ adaptation of the French validation model skills (VAE). Care Talents designed and tested a model for the validation of skills informally acquired by inhome caregivers, with a set of tests / exercises aimed at attesting the possession of the range of skills necessary to perform the tasks related to that profession. The care worker is tested in two sessions of 4 hours each – at the end of the testing process he/she receives a certificate of acquired skills and a training package to fill the remaining gaps. The certificate is currently recognized by a wide range of domestic employment services. Care Talents' tests are available on hard copies as well as on a web-based platform. So far, over 300 care workers have been validated through this methodology. See: www.caretalents.it

See good practices 9, 12, 13, 17

Developing adequate physical infrastructure

Services for older people in need of care and assistance should be provided within adequate physical infrastructures respecting health and safety regulation for users, workers and volunteers, accessibility standards following "Design for All" approaches as well as environmental and energy-saving requirements.

What does it mean?

- An adequate infrastructure is one that supports independent living and good working conditions.
- → The service makes the necessary adaptations to ensure that the infrastructures are fit for older frail and/or demented people, that health and safety rules are adhered to, and that in general staff and users can enjoy clean, safe and healthy surroundings.
- Investments are made according to Design for All principles.

Case example: Ireland

Angela's mother has returned home from hospital after an operation. She is not as mobile as she used to be and finds it difficult to walk. Thankfully she lives in a bungalow and does not have to use the stairs, but Angela is worried about her getting in and out of the bath. She would like her mother to have a shower installed which is easier for her to use. She approaches the local council to see if there are any grants available to help pay for this. She is delighted to find out about the grant for older or disabled people. Her mother applies for the grant which is approved and Angela arranged for the work to be carried out.

Angela also contacts the St Vincent De Paul in Dundalk and applies to get a Personal Panic Alarm for her mother

so that she can summon help if there is an emergency. Angela's mother wants to stay in her own home and with the help of the shower and the personal alarm she is able to do so." (from Ireland, Louth Age-friendly county website)

The **Age-friendly concept** was designed in 2005 by the World Health Organization. The age-friendly city is aimed at encouraging "active ageing by optimizing opportunities for health, participation and security in order to enhance quality of life as people age. In practical terms, an age-friendly city adapts its structures and services to be accessible to and inclusive of older people with varying needs and capacities." A total of 35 cities participated in the first project which developed a bottom-up participatory approach i.e. involving older people in analysing and expressing their situation to inform government policies.

Now, the age-friendly concept is applied to wider geographical areas. In Ireland 'age-friendly county' programmes were developed such as in Louth. In Spain, an 'age-friendly Andalucia' programme was recently put in place. In France, a label 'Ageing well' was open to municipalities across the whole territory. In Germany, plans for age-friendly regions will be developed in the upcoming years. AGE Platform Europe is campaigning to get an **'age-friendly EU by 2020'**, keeping the WHO's holistic approach: outdoor spaces and buildings, transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, community support and health services. www.age-platform.eu/en/component/content/article/1457

See good practice 16

Developing a partnership approach

The development of quality services requires the active involvement and cooperation of all stakeholders from both the public and the private sectors: local authorities, service users, their families and informal carers, users' organisations, service providers and their representative organisations, social partners and civil society organisations operating in the local community. This partnership is essential for the creation of a continuum of services that respond to both individual and local needs, for the effective use of resources and expertise, as well as for achieving social cohesion. Such partnerships are essential for the promotion of age-friendly communities.

What does it mean?

- A good coordination between all those involved will ensure that adequate care is provided in the most effective way to all older persons in need of care and assistance.
- → A partnership approach also ensures that no carer is left alone with sole responsibility to look after a dependent older person to protect her/him from becoming overburdened with care responsibilities.
- A partnership approach also means that responsibilities are clear and privacy protection issues solved, when different service providers are involved.

Case example: Belgium

A municipality wanted to develop a local senior policy plan. In doing so, the policymakers wanted to hear from older people themselves what they wanted and needed. Moreover, they wanted to involve older people in developing and writing the policy plan. The idea sounded great, but they were confronted with the challenge of executing such a task. Because of the high cost of outsourcing this job to a university, it was decided to develop a partnership: local senior advisory boards, older people's organisations, provincial policy makers and researchers were gathered around the table. The aim of this network was threefold: involving older people in (a) research, (b) local policy, and (c) community practice.

The network developed a survey tool to identify the local challenges and opportunities for ageing well. The

emphasis was on the active involvement of older people in all different levels of the project. They decided what was important to measure how they could be involved, which type of trainings they needed, etc. Once the information was gathered, the different partners worked together on developing actions, based on the results of the survey. From the results it became clear that there was a tremendous lack of family caregivers. Whereas informal care is often provided by children, it became clear that this was not the case in this municipality. More older people than average had no children, or had children who lived far away. Based on this result, the municipality developed two main actions. Firstly, they developed a project to recruit volunteer informal carers. Secondly, they increased the capacity of professional home care.

This partnership project turned out to be so successful that other municipalities decided to do the same. In 2012, 160 municipalities participated in the **Belgian Ageing Studies project**. Also several municipalities in the Netherlands and Italy have taken part. One of the important strengths of the project is the local partnership approach. Searching for the benefits of all partners, while diminishing the costs for each partner, generated a high project involvement. www.belgianageingstudies.be

See good practices 2, 11, 12, 16, 19, 24

NeDO

Developing a system of good governance

Services for older people in need of care and assistance should operate on the basis of openness and transparency; respect for international, European, national, regional and local legislation; efficiency; effectiveness; and accountability to service users and public authorities. Services should be coordinated by the relevant public authorities with social partners, civil society and other relevant stakeholders in the design, proper financing (including resources prioritisation within the available budget) and delivery of the service.

What does it mean?

- Rules on paper are not enough, they need to be implemented and their objectives promoted.
- → Good governance requires a concerted effort to aim at quality. It means that all stakeholders are aware of the complexity of needs and expectations of users and other groups, and a general policy framework exists to promote cooperation and integration between the relevant actors.
- → Cost should not be the sole criterion. Quality should play an equal role in decisions made by public authorities about the financing of care services. The process of tendering must be transparent.

Case example: Austria

Mrs. K. was looking for a nursing home for her 89-yearold mother. She wanted to ensure that her mother's habits and personality were taken into account as far as possible and that the staff has good working conditions and thus the atmosphere is relaxed and friendly. Many homes she was checking had a quality management system that sounded perfect in itself. But it was not clear if the personality of her mother would be taken into consideration adequately.

In Austria each Land has its own law for institutional care, and quite different structures. About 25% of all old age and nursing homes in Austria use their own quality management system. As the focus of these systems can differ, the quality of services was not transparent and hardly comparable from the users' perspective. There was no nationwide, uniform, sector-specific independent evaluation procedure for the assessment of the quality of

services provided by old age and nursing homes based on the quality of life.

The voluntary **National Quality Certificate for old age and nursing homes in Austria (NQC)** is a new initiative that attests those homes which apply for and get the certification that the home seeks to advance high quality care and, optimally and efficiently tailors nursing and care services to its residents' needs. While focusing on quality of processes and outcomes, putting in place incentives for continuous improvement of quality in residential care and increasing transparency of care home service provision, the quality of life of residents is at the centre of the National Quality Certificate.

With this procedure and certification, users can see easily if the nursing home meets these criteria. The evaluation outcomes and the strong demand for certification from the homes reflect the smooth functioning of this positive incentive system.

More information: bit.ly/Mf7ATu

See good practices 16, 24

Developing adequate communication and awareness-raising

Services for older people in need of care and assistance and public authorities responsible for them should contribute to ensuring a better communication between all relevant actors as well as promoting a more positive image of older people in the society.

What does it mean?

- → A positive attitude that values older people is promoted throughout the service.
- The service communicates to change negative images of ageing. An objective is to raise awareness of situations of ageism and elder abuse.
- There is effective communication between the different carers, families and the older person in need of care and the outside community.

Case example: Czech Republic

Jana is 88 and took care of her only son all her life. When her son got married, she decided to let him her apartment and to move to a smaller countryside cottage. When he got divorced, he could not continue to live in the apartment and moved to his mother's cottage.

She became ill and less independent. At first she tried to manage herself, but the illness became chronic and she needed to ask for help from her son. Unfortunately he refused to help her and take care of her. Once she realised her money had disappeared. When she asked him, he became aggressive and threatened to hit her, asking her to protect the heritage. Jana felt helpless, and her

neighbours felt they should not intervene as they consider this to be a family issue.

In 2006 a **wide campaign called "Stop elder abuse and neglect"** was led by Zivot 90 in order to raise awareness about the topic. Systematic work was done with the press, media and relevant stakeholders to make this campaign successful.

The first step was to raise public awareness. Posters were made showing pictures of the similarity between elder abuse and child abuse. Those posters were installed on public transport and in the streets. The second step was a campaign in the media: clear explanation with videos and speeches about the topic were sent and disseminated on radio and TV. The Ministry of Social Affairs was a strong partner as they used this campaign on their web pages and to inform key stakeholders as well as social workers. The third step was the dissemination of brochures to help identify the victims.

The brochures were distributed to the places where older people live and where they can pick it up: in doctors' offices, in waiting rooms at the municipalities, seniors' clubs and leisure time activities centres. This brochure tackled the topic in a sensitive way: the purpose was not only to show what could happen but also what are the rights of older people and how the problem of elder abuse could be solved.

This campaign is still ongoing: the brochures are still distributed and reprinted with new information. Continuing campaigns build on the network which was created during this campaign. www.zivot90.cz and www.mpsv.cz/cs/3021

See good practice 11, 15, 19

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Part 2: Guidelines for implementation

The European Quality Framework for services for older people in need of care and assistance can be implemented on a voluntary basis by various stakeholders at local, regional, national and EU level. Its overall aim is **to develop a holistic and coordinated programme of actions all aiming at the same goal: protecting the dignity and improving the wellbeing of older people in need of care and assistance.**

Recommendations for implementation

These recommendations were developed as a result of the input of all national and European coalitions, in particular the experience of the German coalition with the implementation of the German Charter of rights of people in need of assistance, the outcomes of the two WeDO EU events on 21 June 2011 in Utrecht and on 24 April 2012 in Vienna and the steering group members' contributions.

They complement the **national strategies or action plans** developed by the WeDO national coalitions and the EU strategy developed by the EU coalition. To be effective, **they should be used together in a participatory approach** (see the methodology p.32), and be adapted to the national and local contexts.

Recommendations for policy makers

At EU level

- The Social Protection Committee should develop a voluntary European Quality Framework for long-term care inspired by the WeDO quality principles and areas of action, to be adopted by the EPSCO Council as a key element of their Active Ageing principles and legacy of the European Year on Active Ageing and Solidarity between Generations. These principles should then be used in the future by Member States in the framework of their National Social Reports to report on the extent to which their existing national long-term care services respect these principles.
- The European Commission should promote **quality principles for LTC in their upcoming Staff Working Paper and Communication** using the WeDO Quality Framework as a source of inspiration.
- Given the increasing cross-border mobility of older people, care professionals and care providers, the European Commission should provide **adequate information** to older people, their families, care professionals, informal carers and service providers on issues related to cross-border provision of long-term care, quality control, redress mechanisms, etc.
- **Peer reviews and thematic seminars** should be organised on a regular basis on the issue of quality long-term care to enable exchange of experience and good practice on how older people's dignity and wellbeing can be promoted through quality principles and monitoring tools.

At national level

- Member States should adopt a European voluntary Quality Framework for LTC and apply it when reforming their national long-term care, health and social systems.
- If necessary national authorities should develop /adapt existing national quality standards, using the WeDO quality principles and areas of action and involving all relevant stakeholders, including their national coalition if there is one in their country, and share their experience with other EU Member States through peer reviews and thematic seminars.

- Develop comprehensive and independent counselling and information centres for older people, their families, care professionals and service providers on quality services that are available to older people in need of care and assistance.
- Support cooperation between internal and external quality development and control processes, including the provision of counselling, guidance and tools for care organisations on how to implement the WeDO quality principles and how to deal with common structural limitations for the long-term care sector (these might include difficulties with human and financial resources, the lack of accessible outdoor spaces, lacks in the educational system, etc.). Incentives are necessary to guarantee the implementation of quality standards and to enable staff and management to carry out these tasks, for example through training.
- **Implement or adapt existing complaints** procedures with the Quality Framework and strengthen the legal protection of users and carers (e.g. define time frames in which the complaint has to be dealt with). Provide complementary counselling and information on existing rights, both for the user and, if relevant, their third party or advocate.
- Develop quality labelling tools using the WeDO quality principles or integrate them into existing certification/registration or inspection processes to enhance transparency of quality of care for the users. This can be done for example through the development of a checklist made according to the WeDO quality principles.

At local and regional level

- Develop and support regional or local coalitions (or 'care networks') for the dignity and wellbeing of older people in need of care or assistance, involving all the relevant local actors to seek innovative and sustainable solutions for long-term care.
- Promote the European Quality Framework for LTC in the provision of all services to older people in need of care and assistance.

Recommendations for service providers

- Develop and implement **self-evaluation processes** based on the WeDO Quality Principles and areas of action. This should lead to the development of concrete plans for action to improve the quality of life of older people in need of care and assistance
- Develop **training programmes** based on the quality principles for the care staff and informal carers. These training programmes can be developed with the direct involvement of older people in need of care and assistance.
- Use the Quality Framework as an opportunity to develop a new approach to service provision and a **useful tool to support positive competition** in an increasingly competitive sector.

Recommendations for professional carers

• Use the Quality Framework as a basis for discussing how quality of care can be improved at service level.

Recommendations for older people, families and informal carers' organisations

- Use the Quality Framework as a basis for discussing how to improve quality of care and lobby to influence the content of long-term care reform programmes.
- Use it as an awareness-raising tool to improve the quality of life of older people in need of care and assistance and their carers, and to fight against elder abuse.



Examples of quality tools

A lot of quality tools are already implemented in the EU countries at all levels. You can find some examples on the WeDO website www.wedo-partnership.eu, and a selection here below:

A general example

The German Charter of Rights for People in Need of Assistance is a result of the work of the "Round Table for Long-Term Care" initiated in the autumn of 2003 which gathered some 200 German experts from all areas responsible for care in old age. The Charter gives a detailed catalogue of the rights of people living in Germany who are in need of long-term care and assistance. It is also available in English. Several dissemination and quality tools were developed on the basis of the Charter, including an Information Centre on Long-term Care Charter, wide awareness-raising activities (conferences, campaigns, a specialised website, etc.), charter-oriented quality management tools (e.g. selfevaluations, quality circles, mission statements, target agreements) and training material. The Charter is also used to develop external quality control tools and legislation. www.pflege-charta.de and bit.ly/MelgYL

Example of an internal management quality tool

EQalin[®] is a practical and user-friendly model of quality management that is orientated to the needs of the residents, their relatives and the staff of residential care homes. EQalin[®] specifically examines the services delivered in the institutions and their effectiveness in respect to the satisfaction of all people involved. It encourages and formalises the learning within the organisation through self-evaluation and creates scope for innovative improvements and potential development. The system has been developed with the participation of the users. EQalin adopted in the nursing home means that all the collaborators are striving for best quality and are working for the wellbeing of the users. For more information, please visit EQalin's website: www.e-qalin.net

Example of an external quality control tool

The Irish Health Information and Quality Authority (HIQA) is legally responsible since 2009 for the registration and inspection of all public, private and voluntary nursing homes and residential care services for older people in Ireland. HIQA has developed National Quality Standards for Residential Care Settings for Older People in Ireland. These cover: the rights of older people, protection, health and social care needs, quality of life, staffing, the care environment, management and governance. They include supplementary criteria applying to units that specialise in the care of people with dementia. Each residential setting for older people is now required by law to register with HIQA, which must then verify that each centre is fit to operate. This is done through the process of ongoing inspections from HIQA staff both announced and unannounced. Inspectors consult with managers, staff and residents, (if residents wish to be so interviewed), and families. The focus is on the experience of the resident living in the nursing home. An inspection report, naming the residential centre, is posted on the HIQA web site, which also has advice on how to choose a suitable nursing home and the standards that should be expected. www.hiqa.ie.

Example of labelling tool

The German website www.heimverzeichnis.de highlights those care homes in which high standards for the residents' quality of life are achieved. Based on the World Health Organisation's definition of good care, the quality of life is evaluated in regard to the residents' autonomy, participation and dignity using a checklist developed by a wide range of organisations. Data collection is done by trained volunteers. Good practices are published every week on the website. More information: www.pflege-charta.de/EN and section 'European Quality Framework for long-term care services' on the WeDO project website.

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Methodology using a participatory approach

The partnership approach and the 'continuous improvement cycle'

This methodology complements the recommendations for implementation (see previous chapter). It aims at supporting the age-friendly environments movement following the bottom-up participatory approach implemented by the World Health Organization (WHO). It supports the proposal from the Committee of the Regions on implementing an EU age-friendly network and a Covenant of mayors and regional authorities on demographic change involving several governance levels: local, regional, national and EU. The proposed methodology is applied to the long-term care sector.

Consultation, information from and to the grass root levels, sharing experiences are a key element in ensuring the sustainability of the long-term care system. The aim of a participatory approach is to involve all relevant stakeholders at different levels throughout the process of a 'continuous improvement cycle'. This methodology applies to specific initiatives which aim to scale up their results on a wider geographical area or to other working areas. It can be adapted at different levels, from the neighbourhood/service level to the national and EU levels, from very small projects to national or EU-wide ones.

Why is a partnership approach important to drive change? It is important to involve older people, including those in need of care and assistance, and all relevant stakeholders in the process to improve quality care. It helps to develop a bottom up process and can be used to gather the expectations from different target groups. In doing so, a sense of co-ownership of the process can be created among local actors which improves the policy process and helps the acceptance of public authorities' decisions by a wider public as they are better adapted to the citizens' needs. Finally, it ensures that new strategies will be sustainable in the long term.

The WeDO project partners tested the first steps of the participatory approach through the creation of 'national coalitions'. These national coalitions gathered a wide range of organisations working directly or indirectly in the long-term care field, e.g. policy makers, service providers, carers, workers in social and health services, informal care organisations, older people's organisations and representatives from the police. With this methodology, the partnership encourages relevant stakeholders to join the existing national WeDO coalitions (see information at end of document) or if they do not exist, build similar networks at local and regional levels, and to implement their initiatives through a participatory approach.

The methodology

The participatory methodology is made of four main steps: Planning, Implementation, Progress evaluation and Continuous improvement

A. Planning

The purpose of this initial phase is to establish a concerted work plan through finding out what is going well and what is wrong, which practices should remain, identify goals and objectives, and plan for change. Follow the following steps:

Organise a steering group

- Form a team and identify the stakeholders.
- Include older people's representatives specific attention should be paid to cover the needs of frail people, with poor social contacts, whose voices are less easily heard.

Assess what needs to be implemented to ensure compliance with the European Quality Framework

- Analyse the current situation, including existing national/regional/local action plans, collect current performance data.
- Collect data on the needs, expectations and complaints of older people (through questionnaires, consultations, debates) to inform the assessment.

Identify the targets and objectives

- Come up with ideas for solving these problems.
- What are the objectives and goals of the project? What do we want to achieve? What changes do we want to make that will result in the improvement of quality of care? It is important to have a target to focus on and to be able to show the benefits for the organisations involved. Objectives can be set out for the outcome as well as for the process.

Develop a plan of action based on the outcome of the assessment

- Develop ways to make improvements: How will we achieve the objectives? What actions will be developed to realise the goals? At this point the action plan is established.
- Define what different actors can do to achieve the agreed targets and objectives (roles, duties, responsibilities etc.) and adapt their actions, if necessary. Define who should manage the tasks.
- What is the timing of the plan? When will we have meetings, what are the deadlines, what is the time schedule for every phase in the project we want to do? Define the process requirements: What do we need to do?

Identify indicators to monitor progress

• How will we measure whether you have achieved our goals? How will we know that what we changed has brought an improvement? How will we monitor progress at the end of the project?

B. Implementation

At this point it is time to "do", to carry out the action plan.

Introduce changes

The first time, start to implement the change on a small scale, in an experimental phase. This minimises disturbing the routine activity while assessing whether the changes will work or not.

Set up monitoring procedure based on agreed quality principles using the agreed indicators

We should also document the process. For example by recording and describing the way the new process is introduced. We can collect notes of meetings, trainings, actions, etc. We can also take pictures, video tape, etc. Information on number of participants, measures of time, costs, movements, are all valuable knowledge to gather for the next phase.

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C. Progress evaluation

At the end of the implementation phase the steering group has to evaluate whether the objectives formulated in the planning phase are met. Are the changes achieved? Do these changes need improvement? Is the plan working as intended or are revisions needed?

Involve external volunteers to check the objectives with regard to the implementation

- Compare the results with the objectives and goals.
- Use the performance indicators developed in the planning phase.

Define with the steering group recommendations for the next round of actions (improvement cycle)

- Analyse the project regarding the following areas: methods that are used to achieve the objectives, people involved to achieve the objective, equipment, costs, materials, etc. used to achieve the objective.
- Use data gathered throughout the process and the evaluation of the objectives.
- Formulate recommendations: what lessons can we learn from the planning and implementation phase? What was good? What needs to be changed? Where did delays occur and why? Identify any new problems when they arise.

D. Continuous and continual improvement

This phase ensures the long-term value of the project and increases the opportunities of improving quality care.

Continuous improvement: Regular assessment through the ABC cycle (plan - implement - evaluate)

- At this point of the project, we will normally already have achieved some improvement, but not the level that is ultimately perfect. Therefore, after the evaluation, new objectives can be set and new actions can be planned.
- Repeat the cycle of quality improvement and define new opportunities.
- At the start of the next planning phase, the results of the evaluations and the recommendations made are used to determine the objectives and establishing the plan.

In doing so, the cycle is repeated and repeated again and again. Without this step, it is one-time change, and not a cycle of improvement. In a second and third cycle, the implementation of the actions can be done on a larger scale. e.g. from neighbourhood level to municipality to regional to national level, or involving more people, more organisations, more stakeholders.

Continual improvement: establish on-going feedback

Do not wait until the end of the project to evaluate its performance, but use the evaluation process to assess on a daily basis how the project outcome can be improved. Improvement will result from the persistent and iterative application of the planning, implementation and evaluation phases.

Standardise tools

- Cycle 1 often can be seen as a pilot project.
- Use the knowledge gathered from the evaluation cycle to improve and standardise successful tools used in the process ,
- Organise trainings and workshops, develop questionnaires, evaluation matrices, etc. to scale up cycle 1 pilot project.

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Examples of participatory approaches

An exhaustive list of initiatives using the participatory approach and experiences from the WeDO national coalitions can be found on the WeDO website. You can find a selection of initiatives using the participatory method here below:

At national level

The WeDO national coalitions

They were created to gather organisations coming from very different sectors related to long-term care. To contribute to the European Quality Framework and create national strategies, the national coalitions gathered organisations such as: older people's organisations, care homes and home care services, ministries and public agencies, universities and research institutes, organisations fighting against violence, carers' unions and representatives, etc. The creation and coordination of national coalitions was a useful experience for the WeDO partners. You can find the full reports from the national coalitions on the WeDO project website: www.wedo-partnership.eu. Now that the project has ended, the European partnership is opening to all interested parties from all EU Member States and we hope that more countries will join and develop new national and local coalitions.

The experience from the Vrije Universiteit Brussel - Belgian Ageing Studies

The Belgian Ageing Studies team is engaged in the scientific study of the social aspects of ageing. The project developed a research programme that focuses on local challenges and opportunities, as well as issues around quality of life, among home-dwelling older people. The team's research focuses on a range of social gerontological issues, including social, cultural and political participation in old age, volunteering, inclusion and exclusion, age-friendly environments, feelings of safety and the social policy of later life. The project is a result of a close collaboration between the research team, the regional government and councils of all participating municipalities, senior advisory boards, and other stakeholders. Through a participatory method, the older people in need of care and assistance are actively involved as actors in all stages of each study. They play a crucial role in the planning, design, and realisation of the research project, as well as in the development of local policy plans on the basis of the findings of the research. www.belgianageingstudies.be

At regional level

Germany: Guide for the development and implementation of regional networks on dementia

The working group "Networking and neighbourhood work" is part of the Dementia Service of North Rhine-Westphalia. The initiative published a 46-page "Guide for the development and implementation of regional networks for dementia - Recommendations from the field with selected examples". The guide is available only in German and can be downloaded: bit.ly/L8iFFI.

Ireland: The Age-friendly County programme

It aims to create communities where people, as they age, enjoy a good quality of life, and continue to participate fully in the life of the community. The programme is being developed on a phased basis with the ambition that every Local Authority in Ireland will become involved. The programme in each county has a common infrastructure comprising a National Integration Group, County Alliances delivered through the County Development Board, an Older People's Forum and a County Strategy. Age-friendly strategies have already been developed in many Irish counties, such as Louth and Kilkenny. For more information, log on to www.louthagefriendlycounty.ie and www.ageingwellnetwork.ie

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At local level

Improving multi-professional and health care training in Europe (PRO TRAIN)

The PRO TRAIN project (2007-2009) was co-financed by the European Commission Daphne II programme to develop multi-professional training to combat violence in health care. The prjoect aimed at supporting organisations that develop measures and actions to prevent or to combat all types of violence. The training program was designed as two programmes divided into basic modules for multi-professional training and specific modules aimed at health care professionals. The last module within the multi-professional training (module five) focuses on legal frameworks, multi-professional work and multi-agency cooperation including the process of service provision and the meaning of education about the seriousness of violence and its prevention. The last module includes an optimum-model of multi-professional co-operation for violence prevention, which made of five steps: 1) context analysis, 2) strategy and action plan for handling violence, 3) multi-professional working groups on cases of violence, 4) readiness of the multi-professional group to cope with intimate partner violence prevention and 5) what kind of effects do the strategy/action plan and responses to cases have in a multi-professional environment? The model requires a strong involvement of local authorities in building multi-professional groups made of representatives from the police, social services, health professionals, policy makers, educational sector, etc. www.pro-train.uni-osnabrueck.de and training available at bit.ly/SarPAM.

Germany: Continuous Learning Workshop on Dementia in Arnsberg

Supported by the programme, "People in the Community Living with Dementia" of the Robert Bosch Stiftung and inspired by the "Aktion Demenz e. V.", the mayor of Arnsberg started the Arnsberg "Learning workshop" on dementia by working with city officials, citizens and experts to develop a comprehensive community action programme to support people with dementia. All citizens, local authorities, employers, tradesmen and social services were invited to participate under the motto "Together for a better life with dementia". The project's results can be found with the "Handbook for Communities." www.projekt-demenz-arnsberg.de

Germany: WohnQuartier4 (network on local neighbourhood development for older people)

WohnQuartier4 is a pilot project on developing communities with regard to the needs of older people. It acts as a learning network involving administrative and local stakeholders to work on the following four factors 1) housing and living environment, 2) health, service and care, 3) participation and communication 4) education, art and culture. The objective is to link the available housing, social, health and care infrastructure into small-scale offers that can be integrated into residential areas in order to enhance independent living by developing new collaboration models with respect to local needs and resources. www.wohnquartier4.de

At service level

In France, a Council of social life (Conseil de la vie sociale) is set up in each residential institution and is composed of elected representatives of residents, families, and staff. Residents can also regularly meet to discuss meals and other services provided in the institution.

In Belgium, weekly group discussions are held between carers and care recipients. In a care centre in Flanders, the residents participate in their own care through weekly group discussions made of 15 people. They are consulted about what needs to be changed in their care, environment and care centre policy, to enhance their quality of life. A psychologist coordinates these discussions.

In Austria, the Ethical Resident's conference is a setting gathering all relevant stakeholders (older people, the family, the nursing staff, volunteers, doctors, etc.) to speak about ethical issues and ensure that the will of the older person in need of care is respected.

NeDO

We DO for the wellbeing and dignity of older people in need of care and assistance!

You can do a lot starting by small changes. The WeDO partnership is an excellent opportunity to **share your** experiences, get access to innovative ideas. So get involved!

Why to get involved?

Being a member of the WeDO partnership gives you access to an EU-wide community of stakeholders committed to improving quality of long-term care services. You will be able to participate in an online forum, exchange information with other members of the partnership (including the WeDO partners who have already developed national coalitions) and share experiences.

How to get involved?

You can ask to join the partnership by:

- Contacting your national coalition coordinator and take part in their work if you are based in one of the 12 countries involved in the WeDO project (see information below)
- Contacting AGE Platform Europe if your country was not involved in the WeDO project. We will provide you with information and support to help you join the partnership and set up a coalition of stakeholders in your country.
- Implementing the quality framework for long-term care services and send us information how you did it.

The WeDO website is here to help you!

In the WeDO website (www.wedo-partnership.eu) you will find:

- Contact details of all the leaders of the WeDO national coalitions.
- Examples of quality tools.
- An exhaustive database of good practices.
- The online methodology for a participatory approach with more tips and advices.
- A summary of the experiences of WeDO national coalitions.
- A forum where you will be able to discuss with other members of the partnership.

The **national strategies** developed by the WeDO national coalitions are also available on the project website and may be a useful source of inspiration. They will help you build local, regional or national partnerships of stakeholders to support your initiatives to improve quality of life of older people in need of care and assistance.

→ Go to www.wedo-partnership.eu!

Main contact point:

AGE Platform Europe - Rue Froissart, 111 - B-1040 Bruxelles Tel.: +32 2 280 14 70 - Email: info@age-platform.eu with the reference 'WeDO partnership'

Examples of good practices

Many good initiatives are already implemented in EU countries. New initiatives should therefore build on what already exists, with the help of the selection of good practices here below, and of the online database of good practices available here: www.wedo-partnership/good-practices.

Austria

1. Promotion of autonomy by Departments for remobilization and acute geriatrics set up in several hospitals

Patients are helped to reintegrate into their daily lives by temporary treatments in acute geriatrics/ rehabilitation wards (AG/ R). The "activating care" and the therapy are important components in the process. The AG/R ward teams support older people whose autonomy is endangered by making it possible for them to live in their own homes. The team is made up of doctors, nurses and care helpers, therapists, social workers, psychologists, dieticians, priests/ pastors. www.goeg.at/de/Bereich/Akutgeriatrie-Remobilisation-Begleitung-und-Steuerung.html

2. Multi-professional team for dementia service

This service - run by "Volkshilfe", an Austrian NGO, in Burgenland (province of Austria) - offers a free Dementia Hotline , municipal information events, technical lectures about dementia and care, free informative home visits with dementia-checkups and talks about findings, information about occupational therapies, timely individual occupational therapies, group occupational therapies during afternoonmeetings, in senior residences and care homes as well as regular roudtables for informal carers.

www.volkshilfe-bgld.at/Demenzteam

Belgium

 Federations for help and home care, a case manager for older people at home

These federations are networks of professionals set up to help older people to stay at home as long as possible by providing them and their families the professional care and help they need. These multi-disciplinary and decentralized networks coordinate a wide range of services: healthcare (family doctor and hospital), cleaning professionals, support for daily activities, but also with the hairdresser, professionals working to adapt the home, etc. A case manager follows the person and is in charge of contacting the different professionals. It is publicly funded. The Federations also provide mutual services for their members, representing them in policy, administrative support etc.

Links: Fédération Aide et Soins à Domicile (www.fasd. be/fasd (FR)), Fédération des Centrales de services à Domicile (www.fcsd.be/fcsd (FR)), Familiehulp vzw (www.familiehulp.be (NL)), Vereniging van de Diensten voor Gezinszorg van de Vlaamse Gemeenschap (www.vvdg.be (NL)), Wit-Gele Kruis (www.wgk.be).

4. Night care

Belgium has several organisations delivering professional and volunteer night care and night sitting services to frail older people to help them live at home for longer. They also give informal carers respite care so they can deliver care for a longer period. These services also enable older people to return home faster after a period in hospital or rehabilitation centre in the best conditions of safety and wellbeing. Depending on the individual needs a team provides assistance and support, guides the older person toward rehabilitation, promotes selfsufficiency and is responsible for nursing care.

Links: Nachtzorg (www.nachtzorg.be (NL) www.nachtzorgvlaamsbrabant.be (NL),

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www.nachtzorgbrussel.be (NL), Connector Night (public.guidesocial.be/associations/conectarnight-asbl.152087.html (FR)), Infirmières de nuit www.ucp-bruxelles.be/IMG/pdf/Gaz___ electricite_tarif_social.pdf, Nachtopvang at WZC De Vijvers (www.ocmwgent.be/Woonzorgcentra-De-Vijvers.html (NL), Ambulante Nachtdienst aan huis www.ocmw-destelbergen.be/?g=node/98 (NL)

Czech Republic

5. Senior Academy: classes on elder abuse

The Senior Academy organizes seminars for older people to inform them about how to prevent elder abuse. They are specifically targeted at older people and the criminal offences they could experience. Implemented by the Police, they provide information on the various forms of elder abuse, most common perpetrators and how to protect themselves – where to find help and what to do. Police believe that this preventive action helps to reduce the number of cases and to provide solutions when elder abuse occurs. Participants have the opportunity to ask for more information about cases of elder abuse.

6. Quality standards in social care

In these standards, emphasis is put on the dignity, promotion of independence and autonomy of users, their participation in normal life in their natural social settings and especially on the respect for their human and civic rights. The understanding of the principles laid down in this publication will allow service providers to start introducing the desired changes in services even before they are enacted in legislation. The standards describe what a quality social service should look like. They are a set of measurable and verifiable criteria, not a draft law or regulation. Their purpose is to assess the quality of the service provided. www.mpsv.cz/files/ clanky/2057/standards.pdf

Finland

7. Legal entitlement for a needs assessment for people aged 75+

A law entitles every person over 75 years old to have an assessment done within 7 days from request for non-urgent cases. The assessment is made in relation to the needs for services such as home care and housing services, support for informal care, social services (services for disabled people, substance abuse services, social assistance) and residential care. The needs assessment is free of charge. If the older person accepts the assessment, a care plan is made together with the municipality, the older person and his/her legal representative if needed. www.stm.fi

8. Public-funded website to compare health and social services

Palveluvaaka.fi provides information on how health and social services perform. The internet user can compare different services, access the social and health statistics and evaluate the services. Palveluvaaka.fi includes information on health and care services in residential care homes and sheltered housing. The website was launched in 2011 and will be regularly updated to renew and add new information. Palveluvaaka.fi is developed in cooperation with social and health care stakeholders. www.palveluvaaka.fi

France

9. Training programmes for professionals MobiQual

The MobiQual programme is a national initiative which aims to improve the quality of professional services for older people in need of care and assistance and people with disabilities. It is included in public health action plans for older people and is implemented by the Geriatrics and Gerontology Society and supported since 2010 by the National Fund for Autonomy and other relevant ministries. It is aimed at all professionals from the healthcare and social sectors, and covers good care, pain relief, palliative care, depression, nutrition and diet, Alzheimer's disease and infection risks. For each topic, a toolkit is developed for training support and practice of professionals. More information: www.mobiqual.org

nbD

10. Mandatory internal evaluation of care services at home

The certified home care services are obliged by law to undertake an internal evaluation on a regular basis. To help them, there is a specific framework for home care services, which is based on exchange of experiences from professionals and experts involved. A training programme is available and organized by the local social centres. This framework is now being developed online so it can be used for monitoring progress.

Germany

11. The Federal Association of telephone hotlines, counseling and complaint services for older people (BAG)

The Federal Association of telephone hotlines, counselling and complaint services for older people currently consists of 17 different regional helplines. It aims at helping people in need of care and assistance with their grievances, especially in crisis situations, and at reducing deficits of treatment or abuse of older people at home or in nursing homes. The BAG developed standards for counseling and information to support the telephone services. The Working Group was established in 1999. Since 2011 a common web portal provides information about the existing offers in the federal states. www.beschwerdestellen-pflege.de

Nationwide Alzheimer's helpline

The Alzheimer's helpline is a nationwide offer of the German Alzheimer Society for patients with Alzheimer's or other dementia and their families. It supports all people seeking help from professionally trained social workers. The telephone counselling includes medical information on Alzheimer's disease and other forms of dementia, the diagnosis, dealing with difficult behaviors, legal issues and personal concerns. According to the Alzheimer's Association they receive more than 58,000 inquiries per year. www.alzheimer-telefon.de

12. The "Network Care Attendance"

The "Netzwerk pflegeBegleitung" is a national network of 2.500 volunteers who act as care counselors in 150 locations in Germany. They are trained by the adult education centre FOGERA (using a specific training concept) to help and support family carers by giving advice how to organize self-help and use existing care structures. www.netzwerk-pflegebegleitung.de

Greece

13. Online support for caregivers of older people with Alzheimer

Alzheimer's Association Thessaloniki offers the opportunity to caregivers to participate in online support groups for caregivers who live outside Thessaloniki, and for those who cannot attend any meeting because of the continuing care to patients. Participation in the group is free of charge and caregivers that take part in provincial cities are able to interact and exchange views with each other through the online platform used. The purpose of these meetings is: to provide information and practical advice on caring more effectively and to provide emotional support to caregivers in order to address possible negative emotions such as anger, grief, loss and loneliness which can lead to burn-out and elder abuse. www.alzheimer-hellas.gr/english.php

14. Free-Red-Button Service

Life-Line Hellas offers the 24h-call-service of the alarm red button free of charge. People only pay for the equipment. When people cannot afford it, the organization tries to find sponsors such as companies, the Rotarians etc. to cover the costs. Family members, neighbours, volunteers or the police respond to the alarm, if needed.

NeDO

Ireland

15. Positive Ageing Week

The Positive Ageing Week was established by the campaigning charity Age Action in 2011. Positive Ageing Week takes place each year around October 1, the UN International Day for Older People and aims to celebrate the fact that we are all growing older, and to highlight the contribution which older people make. Over the years the Week has achieved a growing support from the general public. Over 1,000 different events take place with hundreds of communities throughout the country participating, each marking the week in their own special way. These are organised by many different organisations including nursing homes, Positive Ageing Committees, housing associations and senior clubs, and take place a wide variety of settings from libraries to galleries, leisure to care centres. In addition a number of Positive Ageing Towns run week-long series of events.

Positive Ageing Week events include music, dancing, art, photography, storytelling, cookery, bowls, guided tours, nature walks, theatre shows, healthy eating, aerobics, vintage car displays, friendship clubs, reminiscence, computer courses, exhibitions, talent contests and many more. www.ageaction.ie

16. Age-friendly counties

Based on the WHO Age Friendly Cities Framework, they aim to create communities where all of us as we age, enjoy a good guality of life and continue to participate fully in community life. The WHO defines an 'age-friendly' community as one in which service providers, public officials, community leaders, faith leaders, business people and citizens recognise the great diversity among older people, promote their inclusion and contribution in all areas of life, respect their decisions and lifestyle choices, and anticipate and respond flexibly to age-related needs and preferences. The programme is currently developed on a phased basis throughout Ireland. The aim is that every Local Authority area will have its own Age-Friendly County Programme involving an Alliance of senior decision makers and influencers across key public, private and voluntary agencies, and an Older People's Forum which is open to all older people to join. The programme is a key initiative of the Ageing Well Network - an independent network of leaders and stakeholders – statutory, public, private and voluntary who share a vision of Ireland *as the best country in the world in which to grow old*, and are committed to achieving it. www.ageingwellnetwork.com

Italy

17. Platform of services and tools for the family caregivers and for domestic care workers

This platform offers a wealth of free information, training and tools available online. A course for family caregivers was tested on more than 200 family caregivers. Tools such as a diary, a questionnaire and a guide on local services are provided to the carers. Specific tools for domestic care workers were also developed: a self-study course, a training programme, a skills validation programme and a diary were also tested on more than 300 domestic care workers. www.caregiverfamiliare.it

18. No alla solit'Udine (not alone)

They are proximity services offered by the Municipality of Udine. They can be contacted through a contact centre open every day from 7 am to 11 pm. Services include: home delivery of medicine, grocery, books, medical prescription; errands and small house repairs ; counselling; company; reading of books. Services are provided by volunteers.

Netherlands

19. 'Valuable care' initiative

LOC, A Voice in Care represents 2,200 service user groups and 600,000 service users in the mental healthcare, social support, nursing and caring, addiction support, homecare and well-being sectors. As the largest association of care clients' councils in the Netherlands, LOC has developed a vision of care that aims to link all levels of society, the care system and care organisations. www.loc.nl/loc/english

WeDO

20. Building blocks for (integrated) multidisciplinary informal care

The system is based on the assumption of a strong inter-relationship between the care recipient and the caregiver. In most cases, difficulties experienced by the care recipient translate into difficulties for the caregiver. Conversely, difficulties experienced by the caregiver are translated into difficulties for the care recipient. These building blocks provide local governments and health insurance companies with insight into which interventions should be performed and by whom, in addition to providing clues necessary for adjustment. www.cmo-flevoland.nl

Slovenia

21. Ljubljana: accessible city

In 2012, the Access City Award was granted by the European Commission to cities with more than 50.000 inhabitants that systematically plan and implement measures to improve the accessibility of their urban environment for vulnerable people. Among 114 cities from 23 EU member states, a group of 8 were selected, Ljubljana being one of them. Information for people with disabilities is available on www.ljubljana.si/si/zivljenje-v-ljubljani/osebe-z-oviranostmi.

22. Counselling helpline on social security and health

Since 2007 the Gerontological Society of Slovenia has been running a counselling telephone line each Wednesday. It offers a variety of information mostly concerning health and social security legislation. In addition to that, the society organizes workshops on topics such as: handling pharmaceuticals in a home environment, self-medication and its limits, healthy nutrition and lifestyles, identification of the early symptoms of dementia.

Sweden

23. Janitor services for Older people

Janitor services for older people have become common in municipalities in recent years and require no entitlement to support. However, there are different rules for the use which varies from municipality to municipality. The janitor service provides practical help with everyday tasks for the prevention of various risks, such as falls. Actions to be performed must be short, but not acute. For example, you can get help to set up and change the curtains, fuses, light bulbs, batteries, hang up and move pictures or shelves, move furniture, pick up and drop things in the attic and storage areas or take down and set things in high cupboards. Last but not least, it helps to prevent injuries by anticipating the risks at home and arrange the cords and rugs if necessary to make your home safer.

24. National core values for long-term care services

The national core values for long-term care services is a new legislation in Sweden (from January 1st 2011) that states that care must focus on the dignity and wellbeing of older people. This means that care should protect and respect everyone's right to privacy and physical integrity, autonomy, participation and personalization. With this legislation municipalities will have to develop a new dignity guarantee and this will be checked by the public authorities. The National Board of Health and Welfare works with the national core values. They will contribute to getting the national core values embedded and applied in practice. The work consists of training material, guidance for local level, website development and information material, a national instrument for needs assessment, etc. www.socialstyrelsen.se/aldre/nationellvardegrund

Europe

25. Breaking the taboo projects

"Breaking the Taboo – Violence against older women within the family: Recognizing and acting" was a European project financed by the Daphne II-Programme. It aimed to raise awareness among the public as well staff members working in older people's own homes (e.g. nurses, nursing assistants, home helpers, social workers) concerning violence against older women in families. The overall purpose of the project was to improve the situation of older women in families by empowering staff members to recognize abusive situations and to help combat them by raising awareness. A second Daphne project "Breaking the Taboo 2" was developed to enable senior staff and/or trainers to carry out awareness raising workshops on "violence against older women within the family - recognizing and acting" with the above mentioned staff members. A training handbook is available on CD-ROM in German, English, Dutch, Bulgarian, Slovenian and Portuguese. www.btt-project.eu

26. Improving Access to Community-based Services for Older People Living at Home (IACS) project

This project, which was co-funded by the European Community Programme for Employment and Social Solidarity PROGRESS, addressed the issue that many older people and their families who are in need of help and care and are otherwise disadvantaged often fail to use existing support services. This is often due to lack of knowledge about opportunities but also due to the negative image of taking up services. Thus strategies for improving access to care counselling for disadvantaged older people and their families were tested in two areas in Austria, Lithuania and Poland. These strategies involved mediators from health and social care services such as doctors or social workers, mediators from other areas, such as seniors' associations, cultural or migrant associations or the church as well as networking activities between both fields. During the research process on the access strategies, preliminary data was collected from 539 people, 77% (415) of these people took up care counselling. Recommendations are available in English, German, Polish and Lithuanian. www.roteskreuz.at/pflege-betreuung/projekte

27. Empowering Health Learning for Elderly (EHLE) project

Empowering Health Learning for Elderly (EHLE) Project aims at improving skills and competences of professionals working with older people, by creating innovative training models; it is also intended to share knowledge and experiences between partners in order to obtain relevant results in the field of lifelong learning for older people. Finally, training material and training aids based on these results will be produced and distributed on the territory. The EHLE Project is funded by the European Commission under the Lifelong Learning Programme - Grundtvig. www. ehle-project.eu

28. Monitoring in Long-Term Care – Pilot Project on Elder Abuse (MILCEA) project

The main thrust of the Milcea project is to provide a framework for European countries on how to put in place the structures needed to monitor elder abuse. The framework has been developed for use in all European countries, and has been evaluated by several international experts in the field of elder abuse and / or long-term care. The project was funded by the European Commission results can be found at www. milcea.eu.

NeDO

Useful resources and interesting links

Official documents

European voluntary Quality Framework for social services ec.europa.eu/social/main.jsp?catId=758&langId=en

European Parliament Resolution on long-term care www.europarl.europa.eu/charter/pdf/text_en.pdf

United Nations Convention for the rights of persons with disabilities www.un.org/disabilities

United Nations Action Plan on Ageing www.un.org/esa/socdev/ageing/madrid_intlplanaction.html

World Health Organization, Preventing elder mistreatment www.euro.who.int/__data/assets/pdf_file/0010/144676/e95110.pdf

World Health Organization, Guide to Age friendly cities www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf

OECD study: Help wanted? Providing and paying for Long-term Care www.oecd.org/document/15/0,3746,en_2649_37407_47659479_1_1_37407,00.html

EU Projects

Milcea www.milcea.eu (framework on elder abuse prevention in the EU)

Eustacea (EU Charter of the rights and responsibilities of older people in need of care and assistance) www.age-platform.eu/en/daphne

Breaking the taboo www.btt-project.eu

EURoPEAN www.preventelderabuse.eu

INTERLINKS

interlinks.euro.centre.org (information on long-term care with practice examples)

Ancien

www.ancien-longtermcare.eu (analysis of long-term care systems in several countries)

AVOW

www.thl.fi/en_US/web/en/research/projects/avow (study on violence against older women)

IPVOW and Mind the Gap

ipvow.org and zoom-institute.eu/projects/current-projects/-mind-the-gap

IACS

www.roteskreuz.at/pflege-betreuung/projekte

List of partners

Project leader



AGE Platform Europe is a European network of around 165 organisations of and for people aged 50+ which aims to voice and promote the interests of the 150 million senior citizens in the European Union and to raise awareness on the issues that concern them most. www.age-platform.eu

European organisation



E.D.E is a **European Association for Directors and Providers of Long-Term Care Services for the Elderly.** Members in E.D.E. are organisations of home directors coming from 18 European countries and altogether there are 23 national associations. www.ede-eu.org

Austria



AUSTRIAN RED CROSS

The Austrian Red Cross, founded 1880, is a private independent NGO and member of the International Red Cross Movement. It is guided by the fundamental principles of the Red Cross Movement and its volunteers and employees engage in many humanitarian activities to help the most vulnerable in society, both nationally and internationally. www.roteskreuz.at/i18n/en/

Belgium



Vrije Universiteit Brussel

The Belgian Ageing Studies (BAS) have emerged from the need to execute an environmental analysis of the neighbourhood which includes the potential of facilitating social change in the locality regarding older individuals. The main objective of the project is to support local policymakers, professional stakeholders and individual or organised older people in the development of a local policy plan for older people. www.vub.ac.be

Czech Republic



Život 90 is a NGO helping older people to actively and meaningfully live in their own home as long as possible. Our goal is to improve the quality of life in general by supporting older people and their right to dignity. Život 90 offers social services including respite care, home care, a Senior Telephone help line, counselling courses, and training and theatre performances. www.zivot90.cz

Finland



NATIONAL INSTITUTE FOR HEALTH AND WELFARE

The National Institute for Health and Welfare (THL) is a research and development institute under the Finnish Ministry of Social Affairs and Health.THL works to promote the well-being and health of the population, prevent diseases and social problems, and develop social and health services. www.thl.fi



The University of Helsinki Palmenia Centre for Continuing Education is the largest and most multi-disciplinary unit of its kind in Europe. Through Palmenia, people can receive the latest research-based information and university-level expertise to support your personal development, or the development of their own organization. www.helsinki.fi/palmenia

France

fng

The FNG (National Foundation of Gerontology) is a national resource centre working on older people and ageing. It developed for the first time in 1987 a "Charte des droits et libertés de la personne âgée dépendante" (Charter of the Rights and Liberties of dependent elderly people). www.fng.fr



The National Union of Social Action Community Centres (CCAS) is an association which brings together 4,000 CCAS and 6,000 municipalities and / or cooperation between neighbouring communes' organisations. UNCCAS has as its main objective to promote and defend the social action of proximity implemented by the social centres. www.unccas.org

Germany



The Federal Association of Senior Citizens Organisations (BAGSO) aims to represent the interests of the older generations in Germany, especially to ensure that every human being has the possibility of a self-determined life in old age and to get the opportunities for it. BAGSO represents 102 associations, organizations and initiatives working together, representing about 13 million older people in Germany. www.bagso.de

DZA German Centre of Gerontology

The **German Centre of Gerontology** is an institute for scientific research and documentation in the fields of social and behavioural ageing research. DZA worked on the follow up of the German charter of the rights of people in need of long-term care. www.dza.de



ISIS is a private institute for applied social research, social planning and policy advice. ISIS is involved in the internal evaluation of the WeDO Project. www.isis-sozialforschung.de

Greece



50plus Hellas is a Non-governmental and not-forprofit organisation which aims to improve the quality of life of those over 50 years of age in Greece, within a more equal society and through actions and activities affecting all aspects of life. www.50plus.gr/english

NeDO



Third Age is a voluntary, community organisation which aims to empower local communities throughout Ireland by promoting to best effect the resource its older people represent.

www.thirdageireland.ie



Anziani e Non Solo is a cooperative society working since 2004 in the field of social innovation, with a specific focus on management of project and promotion of products and services in the field of welfare and social inclusion. www.anzianienonsolo.it



FIPAC is a large and representative organisation of older people in Italy whose aim is to improve the services provided to older people, to protect their dignity, and to increase their financial independence. www.fipac.it



ANBO is an association in the Netherlands representing senior people. Our primary goal is to provide independence and to promote the interests of seniors to national, provincial, and local governments and authorities. www.anbo.nl

Slovenia



Mestna zveza upokojencev Ljubljana (MZU Ljubljana) is a federation of 101 local older people's associations with more than 30.000 members and four decades of the tradition. www.mzu.si

Sweden



SENIORER I TIDEN

SPF was the first Swedish organisation for pensioners, established in 1939. SPF is a politically and religiously independent organisation and has approximately 270,000 members in the 850 clubs divided in 27 districts throughout the country. www.spf.se

This Quality Framework is also supported by:



The European Centre for Social Welfare Policy and Research: UN-affiliated intergovernmental organization concerned with all aspects of social welfare policy and research. www.euro.centre.org

Eurocarers, European Association Working for Carers, seeks to represent and act on behalf of all informal carers, irrespective of their age or the particular health need of the person they are caring for. www.eurocarers.org

The European Social Network (ESN) brings together people who are key to the design and delivery of local public social services across Europe to learn from each other and contribute their experience and expertise to building effective social policy and practice.

A special thanks to all the organisations involved in the national and EU coalitions who contributed to the content of this document.

WeDO is a European project (2010-2012) co-financed by the European Commission. It was led by a steering group composed of 18 partners from 12 European Union (EU) Member States interested to work together on the improvement of the quality of life of older people in need of care and assistance.



Contact

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We can **DO** a lot starting by making small changes.

The WeDO partnership is aimed at any stakeholder who would like to improve the quality of life of older people in need of care and assistance, through the implementation of the EU quality framework for long-term care services.

The WeDO Partnership is an excellent opportunity to share your experiences, get access to innovative ideas.

→ So get involved! Become members of the partnership!

More information at www.wedo-partnership.eu

In the WeDO website you will find:

- Contact details of all the leaders of the WeDO national coalitions and a summary of their experiences during the WeDO project
- More examples of good practices and quality tools
- An online methodology for a participatory approach with more tips and advices
- A forum where you will be able to discuss with other members of the partnership

The EU Quality Framework for long-term care services contains:

- Quality principles and areas of actions to improve the wellbeing and dignity of older people in need of care and assistance
- Guidelines for implementation
- A selection of good practices and useful links



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