



Dignity and wellbeing of older persons in need of care

Our shared responsibility

Toolkit for policymakers and practitioners



This toolkit is available online:

<http://publications.age-platform.eu/opcare-toolkit/>

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Introduction

“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 Rights and Responsibilities of older people in need of care and assistance, EUSTaCEA project, 2010

Why this toolkit?

This toolkit is aimed at policymakers and practitioners who would like to evolve towards ensuring the wellbeing and dignity of older persons in need of care. It shows how they can adopt a rights-based approach in long-term care policies and daily practice.

It has been developed by AGE Platform Europe, a Europe-wide platform of organisations advocating for the rights and wellbeing of older persons. AGE aims to voice the interests and expectations of the 30 million older persons who belong to its member organisations, by facilitating the exchange of views and practices and influencing the policies of European Union institutions.

This toolkit provides essential information on the current policy and legal instruments in the field of the rights of older persons in need of care and support. It gathers evidence, ongoing policy processes and the existing legal and policy frameworks to help formulate policy responses that adopt a rights-based approach to care. This toolkit also includes practical tools to enforce, in everyday care delivery, the rights and dignity of older people in need of care.

With this toolkit, **AGE also aims to highlight** how policymakers and practitioners can concretely improve the enforcement of the rights of older persons in need of care, and promote their dignity and wellbeing.

It aims to be relevant at all levels, for a wide range of health and social care managers and practitioners, civil society organisations, policy planners, etc. Whether you are involved in designing or monitoring policies, or in their implementation of policies, or in their implementation, we hope that this toolkit will help you in your role to enforce the rights of older persons in need of care in practice and that it will trigger concrete action on the field. We also hope this toolkit will act as a catalyst to enable stakeholders at all levels and in all relevant fields to work better together to guarantee a dignified life for persons as they age.

The content of this toolkit is based on accumulated knowledge over the last years in the fields of the fight against elder abuse, quality care and human rights at European and international level. In particular, it is inspired by the numerous exchanges of experiences held in two European projects (**EUSTaCEA** and **WeDO**), the expertise of AGE members and partners, and the events organised annually to mark the World Elder abuse awareness day supported by the European Commission, the Council of Europe, and the United Nations Office of the High Commissioner on Human Rights.

The toolkit includes:

- an overview of the current legal and policy framework in the European Union protecting older persons in need of care (**Part 1**) and of international instruments and processes (**Part 2**)
- an overview of the challenges faced by many older persons throughout Europe, and what AGE has identified as key priorities for action at EU level (**Part 3**)
- a toolbox to help policymakers and practitioners promote the wellbeing and dignity of older persons in need of care in practice (**Part 4**)

The online toolkit is available online [here](#)

For questions and further information, please contact Borja Arrue, Policy and Project Officer responsible for long-term care and elder abuse at borja.arrue@age-platform.eu or AGE secretariat at info@age-platform.eu.

This toolkit was conceived and edited by Maude Luherne, member of AGE Platform Europe staff until 2016. **We thank all those who contributed to this toolkit**, and in particular Anne-Sophie Parent, AGE Platform Europe Secretary General, Nena Georgantzi, AGE Platform Europe policy officer on human rights, the members of the WeDO partnership and of AGE task force on Dignified Ageing who continuously share their experiences, knowledge and information on how to improve the wellbeing and dignity of older persons in need of care.

What is that?

Click on the image or [here](#) to open the video on your internet browser



What is That ? A Sparrow

This video was used in the [WeDO2 Quality care training package](#)

A short quiz to start: did you know...?

This introduction quiz is not aimed to test your knowledge but rather highlight essential data in the field of care for older persons, before going into more details.

Question 1/3: How many older persons do you think lack access to quality long-term care in Europe?

- 50%
- 30%
- Less than 10%

Question 2/3: What would you think the prevalence of elder abuse cases among older persons with high care needs in Europe is?

- 7.5%
- 18%
- 25%

Question 3/3: Which country do you think ranks first in 'providing opportunities for social contacts among the older population'?

- Greece
- Spain
- Denmark

[Answers are available on the page that follows]

Answers

Question 1/3: How many older persons do you think lack access to quality long-term care in Europe?

Answer: 30%. According to the International Labour Organisation study released in 2015 on [“Long-term care protection for older persons: A review of coverage deficits in 46 countries”](#), half of the world’s older persons lack quality long-term care. In Europe, it is estimated that 30% of older persons lack access to quality care (for information in America, the figure reaches 15%). However, it also states that national figures “vary significantly”. The study also reveals a global shortfall of 13.6 million care workers, and 2.3 million for Europe (in America, the shortfall is of 1.6 million).

Question 2/3: What would you think the prevalence of elder abuse cases among older persons with high care needs in Europe is?

Answer: 25%. According to the [World Health Organisation - European region report on ‘Preventing elder maltreatment’](#) released in 2011, the prevalence of elder abuse among older persons with high care needs is 25%, and estimates shows that it is underreported by as much as 80%.

Question 3/3: Which country do you think ranks first in ‘providing opportunities for social contacts among the older population?’

Answer: Denmark. According to the report [‘Facts and figures on healthy ageing and long-term care’](#) released in 2012, the lack of social contact of the older population (aged 65 or over) ranges from 3-4% (the Netherlands, Denmark) to over 40% (Greece, Hungary). The same report adds that social isolation increases with age, and is even more prevalent among the population aged 80 or over in all countries.

Glossary

Note: this glossary was mainly elaborated during the two-year EU-funded project called WeDO: Wellbeing and dignity of older persons

Active ageing: This concept refers to “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 well-being 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, Active Ageing: a policy framework)

Dignity: The equal and inherent value of every human being. Dignity is considered to be the foundation of human rights, in the sense that every person deserves be treated with dignity by virtue of being human.

Human rights: Entitlements and freedoms of all human beings, whatever our nationality, place of residence, sex, age, national or ethnic origin, colour, religion, language, or any other status. Human rights are held by all persons equally and universally. They are based on core principles like dignity, fairness, equality, respect and autonomy. Human rights are present in our day-to-day lives and protect our freedom to control the different aspects of our own lives.

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. Usually they do not have a formal status and are often 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’: These encompass prevention, rehabilitation and enablement, cure and care, palliative and end-of-life care. They combine health and social care in support of 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: Right of older persons to be actively involved in all spheres of public life. For older persons in need of care and assistance, this also means the development of 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. Support for active participation should be available 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 the exercise of 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, and attain or maintain the best possible health and integration 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**.

ACRONYMS

AGE	This is not an acronym, but the short name for the organisation AGE Platform Europe
CoE	Council of Europe
DG EMPL	Directorate-General for Employment, Social Affairs and Inclusion of the European Commission
ENNHRI	European Network of National Human Rights Institutions
EU	European Union
EUSTaCEA	European Strategy to Combat Elder abuse
ILO	International Labour Organization
LTC	Long-term care
MIPAA	Madrid International Plan of Action on Ageing
OEWGA	Open Ended Working Group on Ageing
SPC	Social Protection Committee
UN	United Nations

UNCRPD	United Nations Convention for the Rights of Persons with disabilities
WeDO	Wellbeing and Dignity of Older persons
WHO	World Health Organisation

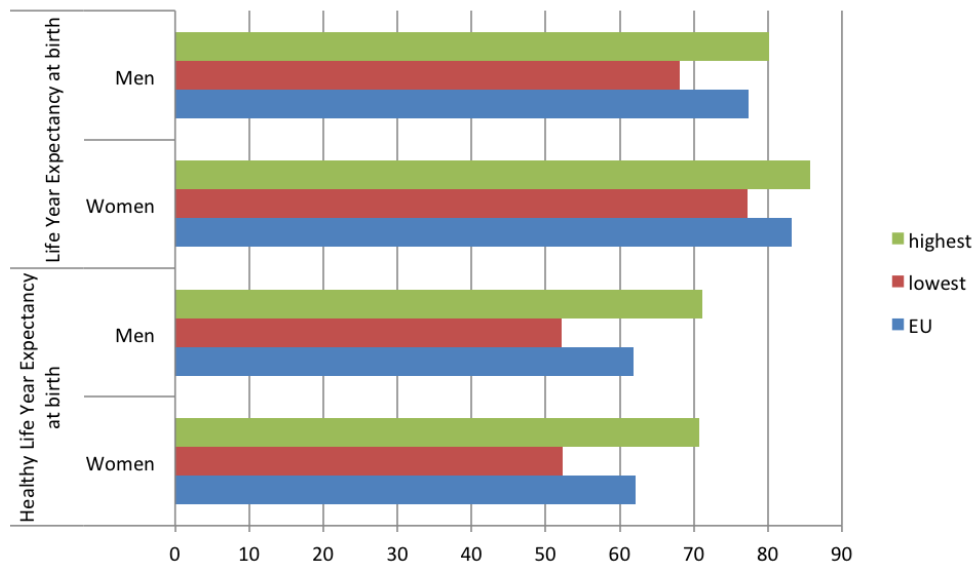
Some key ideas and figures

The top-six reasons why long-term care and the dignity of older persons in need of care should be a priority for action at all levels

1. Access to long-term care is not a cost, a burden or a problem, but a **right of older people and an investment for the dignity of all persons as they age.**
2. Facing functional limitations is an **inherent life risk** that merits a comprehensive response, through the development of **universal long-term care systems in all countries.**
3. **Long-term care needs should not lead to increased risk of poverty** of older persons and their families; reducing public spending on health and long-term and increasing out-of-pocket expenses is not a sustainable solution.
4. **Preventing long-term care needs with adequate rehabilitation services and making care an attractive career option** are far more efficient ways to address the shortage of services than calling exclusively on volunteers or increasing the burden on family responsibility.
5. Investing in long-term care means **investing in new employment opportunities; this requires developing professional skills and improving working conditions in order to offer quality** support services for the benefit of society as a whole.
6. Ageing in dignity is or will become a concern for all of us; **we all have a vested interest in taking action to enforce the rights of older persons in need of care** as well as ensure the quality of life of future generations of older people.

Some key figures

- It is expected that those aged 65 and over will become a much larger share (rising from 18% to 28% of the population), and those aged 80 and over (rising from 5% to 12%) will almost become as numerous as the young population in 2060. [...] The projections show large and sustained increases in life expectancy at birth, albeit with a considerable degree of diversity across Member States ([European Commission Ageing Report, 2015](#)).
- In 2009, men and women in the EU27 at age 65 could expect to live more than half of their remaining years with a frailty or disability that could affect their ability to manage instrumental and/or self-care activities of daily living ([European Commission Staff Working document on long-term care, 2013](#))



Source: Eurostat

- More than half of the world's older persons lack quality long-term care, 30% in Europe (ILO [study](#) Long-term care protection for older persons: A review of coverage deficits in 46 countries, 2015)

- Prevalence of elder abuse for older persons with high care needs reaches 25 %; in addition, it is estimated that up to 80% of cases of elder abuse are not reported **(WHO European report on preventing elder maltreatment, 2011)**.
- 13 out of 14 OECD countries show growing concern about waiting times for LTC services and about half collect data on waiting times to access long-term care **(OECD publication 'A good life in old age', 2014 from a 2012 survey)**
- Over 90% of people providing informal care on a regular basis have a family relationship to the people they care for. Informal carers are typically spouses, middle-aged daughters or daughters-in-law. [...] Estimates suggest that the economic value of unpaid family care as a percentage of the overall cost of long-term care in EU Member States ranges from 50 % to 90% **(EC-SPC report on adequate social protection for long-term care needs)**

Part 1:

The state of play on the rights of older persons in need of care and support at international level

PRELIMINARY REMARK

AGE Platform Europe developed an '*Older persons' self-advocacy handbook*' which intends to increase and improve the involvement of older persons in all processes that affect their human rights.

In this handbook, more detailed information can be found on how the United Nations, the Council of Europe and the European Union address the rights of older persons. Readers can understand better how to implement these policy guidelines and participate in the relevant policy making processes. To access AGE Handbook, click [here](#).

In theory, older persons in need of care and support have the same rights as everyone else. In reality however, they face every day concrete obstacles specific to their age and their living conditions. Older people face **concrete (structural) barriers enshrined in law or policy**, or **ageist attitudes** by society as a whole, media, and including by some professionals and families. These result in age discrimination and lack of access to essential goods and services, lack of access to trained and competent professionals and lower quality of service provision, decreased access to healthcare or opportunities for social participation, absence of financial support for long-term care, neglect and abuse.

A number of processes in the United Nations, at the Council of Europe and the European Union have set to address these issues.

The United Nations framework

The United Nations (UN) has established several instruments and processes that relate to the rights of older persons in need of care and are further described below:

- The UN Principles for Older Persons
- The Madrid International Action Plan on Ageing (MIPAA)
- The UN Convention on the rights of persons with disabilities (UNCRPD)
- The Open-ended Working Group on Ageing (OEWGA)
- The Independent Expert on the enjoyment of all human rights by older persons

The UN Principles for Older Persons

The United Nations Principles for Older Persons were adopted in 1991. Although they are not binding, governments are encouraged to take them into account when they develop laws and policies that target this group. The 18 principles are an important benchmark for all stakeholders who deal with older people.

These principles address 5 key areas of older people's lives:

1. Independence
2. Participation
3. Care
4. Self-fulfilment
5. Dignity

You may find the [UN Principles for Older Persons here](#).

The Madrid International Action Plan on Ageing (MIPAA)

Adopted in 2002, the [Madrid International Plan of Action on Ageing](#) “aimed to mark a turning point in how the world addresses the key challenge of building a society for all ages”.

It represents the **consensus** of the international community to take action on **three priority areas**: older persons and development; advancing health and well-being into old age; and ensuring enabling and supportive environments.

The action plan is an **important resource for policymakers, practitioners but also for non-governmental organizations and older citizens**. It establishes a comprehensive agenda that governments should implement through dedicated action.

To monitor how far they deliver their political commitments and to suggest further action, **governments need to report on their achievements every 5 years**. The next review of the implementation of the MIPAA will be concluded in 2017.

The MIPAA includes a full range of relevant articles on the rights of older persons in need of care, covering caring responsibilities in employment, support for independent living in rural areas, intergenerational support, and address poverty among the oldest old.

In particular, the most relevant are:

- **Priority direction II: Advancing health and well-being into old age**

Issue 2: **Universal and equal access to health care services**, promotion of a 'continuum of care' (health care, long-term care, palliative care, social services), and of prevention and rehabilitation, strengthen access to primary healthcare, tackle 'age discrimination and age-related disability discrimination in the provision of services' and include older persons in the development and improvement of primary and long-term care services

Issue 4: **Training** of care providers and health professionals, including informal carers, and support an integrated approach in care, with gerontologic and geriatric skills

Issue 6: **Maintain the maximum functional capacity** throughout the life course and promote the full participation of older persons with disabilities

- **Priority direction III: Ensuring enabling and supportive environments**

Issue 1: Housing and the living environment with a specific emphasis on the promotion of 'ageing in place' in the community and support **independent living**, multigenerational co-residence and use of technologies

Issue 2: **Care and support for caregivers**, in particular through adequate public policies and social support systems, adequate assistance from formal care services and informal carers through a 'continuum of care and services', with an emphasis on 'older women'

Issue 3: **Eliminate all forms of neglect, abuse and violence of older persons** and create support services for victims of abuse, and train professionals. Consumer fraud is also covered

To support the implementation of the MIPAA, European States have adopted a Regional Implementation Strategy, which provides a list of envisaged relevant ageing policy development in the region.

This regional strategy includes the commitment to ensure quality of life at all ages and maintain independent living, including health and well-being (Commitment 7).

Both the MIPAA and its Regional Implementation Strategy are important reference documents not only for policymakers but also for practitioners in the field of long-term care, as they set out policy objectives but also indications on how to achieve the desired outcomes.

FOR MORE INFORMATION:

- [Full European Regional Implementation Strategy](#)

- [AGE's contribution to the 2016 review of the MIPAA](#)
- The MIPAA: [Full text in English](#) and in [other languages](#)
- More information on the MIPAA [in AGE's handbook on older persons' human rights](#)

The United Nations Convention for the rights of persons with disabilities (UNCRPD)

The United Nations Convention for the rights of persons with disabilities (UNCRPD) is the latest international human rights treaty and the first one to be ratified by the European Union. This means that **all EU member states which ratified it as well as the EU need to make sure that their policies are in compliance with the standards set by the Convention.**

The UNCRPD is relevant for older persons in need of care as it defines persons with disabilities as follows: *“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”*

Whereas the UNCRPD does not address the full range of challenges faced by older persons in need of care, and in particular those situations related to ageism and age discrimination, it **covers many important aspects of older persons' lives**, including access to disability benefits, health services, support for independent living, fight against violence and abuse, accessibility and others.

FOR MORE INFORMATION:

- Full text of the [**UNCRPD**](#).

- How the UNCRPD and applies to older persons with functional limitations in [AGE self-advocacy handbook on the rights of older persons](#).

A committee of independent experts is responsible for monitoring how States and the EU implement the UNCRPD. This Committee can publish for example guidelines on how the right to independent living should be applied in practice, and contribute to the reflection on how the UNCRPD concretely applies to older persons in need of care.

The Committee already acknowledged that: *"the international standards adopted in the Convention on the Rights of persons with disabilities (CRPD) entirely apply to older persons"* ([see full position here](#))

This means that age alone cannot be used to limit from the application of disability policy and legislation to older people in need of support. **Governments that exclude older people with disabilities from accessing related benefits and services, such as disability allowances or personal assistance are actually violating the UNCRPD.**

Stakeholders, including service providers should also look at how to adapt their practices to comply with the UNCRPD principles, since they are responsible to apply the Convention as it has been translated into national law.

AGE Platform Europe monitors the implementation of the UNCRPD so that older people in need of care and assistance enjoy the same standards of support as younger people with disabilities. For example, we submitted our views to the UNCRPD Committee and the UN Special Rapporteur on Disability highlighting the age-specific barriers faced by older persons, in particular the unequal availability of benefits for older people with functional limitations and/or support needs in comparison with younger persons with disabilities.

The Open-Ended Working group on Ageing (OEWGA)



In 2010, the United Nations General Assembly established the Open-Ended Working Group on Ageing (OEWGA), the first global process that has been set up to specifically examine what UN Member States

can do so that older people can fully enjoy their human rights. The OEWGA aims to evaluate existing international instruments and to consider the need and feasibility of introducing new measures and legal tools, such as a new binding treaty.

AGE Platform Europe has taken part in the OEWGA sessions since 2012, bringing the voice of European senior citizens. Long-term care and elder abuse have been central themes of the OEWGA. These discussions are relevant for policymakers as well as legal professionals, service providers and other stakeholders working in the field of ageing, because they shape a new rights-based vision for long-term care.

FOR MORE INFORMATION ON THE OEWGA:

- [OEWGA website](#)
- Dedicated part in [AGE's handbook on the rights of older persons](#).

The Independent Expert on the rights of older persons

In May 2014 Ms. Rosa Kornfeld-Matte from Chile was nominated as the first Independent Expert on the Enjoyment of all Human Rights by Older Persons.

The expert has in her mandate to monitor, evaluate and report on the state of older people's rights on a worldwide level, identifying both good practices and protection gaps.

In her [report on care and autonomy](#), Ms. Kornfeld-Matte highlighted the risk of human rights violations in the context of care provision to older people. She emphasized that the responsibility for levying barriers to autonomy lies with the state and clarified governments' obligations, which include affording adequate resources and promoting a rights-based culture of care.

In her report she also focuses on the wide range of issues related to legal capacity, the development of adequate social protection and standard of living as well as the rights to work, housing, accessibility, participation, social inclusion and health.

She also covers particular aspects of care institutions, including the need for quality control and assessment to prevent and fight elder abuse, as well as access to palliative care. Finally she makes some recommendations to Member States, including the development of comprehensive national ageing strategies and the establishment of national councils on ageing.

Overall, the Expert **provides in her report specific guidelines for the exercise of the right to care and autonomy** and calls for 'a paradigm shift that focuses on the inclusion of older persons in society at all levels, encompassing age-friendly communities and environments, as well as people-centred models of care, and that promotes the autonomy and dignity of older persons'.

Ms. Kornfeld-Matte was also invited by the Slovenian and Austrian governments to take part in country visits to evaluate the current state of protection of the human rights of older people.

Her speech on the 15th June 2015 is available here:

<https://www.youtube.com/watch?v=6FgTn1BDg4s&feature=youtu.be>

FOR MORE INFORMATION:

- [Website of the Independent expert](#)

- [The report on 'care and autonomy'](#)

Council of Europe's framework

The Council of Europe (CoE) includes several instruments for the protection of older people's rights.

- The **European Convention of Human Rights** is the main CoE human rights instrument and is monitored through the [European Court of Human Rights](#) based in Strasbourg, France.

While it does not explicitly refer to old age, older persons, or care the interpretation of the Convention by the European Court of Human Rights has paid significant attention to human rights in the context of eldercare. A factsheet summarizes the most relevant case law of the Court for older people, including those in need of care, [here](#).

For example, the McDonald vs UK ruling showcased that the absence of an adequate care plan can amount to a breach of the rights to dignity and private life of the older person.

- The **European Social Charter** was adopted in 1961 and revised in 1996 to guarantee social and economic rights.

Article 23 of the revised charter –the first binding human rights provision for the protection of older people – enshrines the right of older persons to social protection including access to information about services and facilities available for older persons, provision of housing suited to their needs and their state of health or of adequate support for adapting their housing and access to health care and services.

- **The Committee on Social Rights** oversees the implementation of this treaty and has for example ruled that the system of financial support for family and friend

caregivers should not depend on their place of residence, as this would imply an unequal application of the European Social Charter. (Case of Central Association of Carers in Finland). Following this deliberation the Committee of Ministers of the CoE addressed a recommendation to Finland asking the review of its national legislation.

NGOs which think that national laws and policies are in violation with article 23 of the Charter, can submit related complaints to the committee once they have been granted the right to participate in this procedure.

- **The European Committee for the Prevention of Torture** is an independent body of experts which has the mandate to visit institutions where persons are deprived of their liberty, including nursing homes and other social care facilities. Based on their visits they draw recommendations to the government concerned on how to improve the quality of life of people in living in such institutions in the country
- **The Convention on preventing and combating violence against women and domestic violence** (Istanbul Convention), provides a legal framework and a monitoring mechanism for the protection of women from all forms of violence. Its scope includes abuse against older women. A number of European networks of NGOs, including AGE, [has called the European Union to access this Convention.](#)
- The **Recommendation on the rights of older persons**, which is the first regional instrument specifically protecting this group. It will be explained more in details below.

MORE INFORMATION:

- [Activities of the Council of Europe on older persons' rights](#)

Focus on the Council of Europe's recommendation on the rights of older persons

The Council of Europe adopted in 2014 a recommendation focusing specifically on the rights of older persons. Although non-binding, this instrument is a **useful advocacy tool for the rights of older persons in Europe**.

The recommendation also foresees a review 5 year after its adoption, when States will submit reports assessing progress in its implementation.

It takes inspiration from several reference documents, including the [European Charter for the rights of older persons in need of long-term care and assistance and its accompanying guide](#).

The recommendation covers the rights of older persons in need of care, and in particular includes a detailed chapter on 'Care' divided into **four areas: general principles, consent to medical care, residential and institutional care and palliative care**.

This recommendation highlights for the first time older people's **right to care**. The recommendation stresses the need to prevent and address elder abuse and emphasizes the role of informal carers, as well as the responsibility of states to provide them with adequate support and training. It also addresses the areas of non-discrimination, autonomy and participation, and administration of justice. The recommendation also provides **guidelines** on ways to apply it in practice in its explanatory memorandum and a list of good practice examples.

“Older persons have the right to respect for their inherent dignity. They are entitled to lead their lives independently, in a self-determined and autonomous manner. This encompasses, inter alia, the taking of independent decisions with regard to all issues which concern them, including those regarding their property, income, finances, place of residence, health, medical treatment or care, as well as funeral arrangements. Any limitations should be proportionate to the specific

situation, and provided with appropriate and effective safeguards to prevent abuse and discrimination.”

(Art. 9 of the recommendation)

Although Member states are not legally bound by this instrument, they have committed politically to do more to put the rights of older people in effect. The Recommendation complements existing binding human rights treaties.

As it provides specific policy guidance, it has a real potential for impact on the ground if governments take it into account in their policymaking.

This is why it is **important to raise awareness about the existence of the instrument**, and for policymakers and practitioners to use it as a reference document.

MORE INFORMATION:

- [Council of Europe Recommendation](#)

Role of the World Health Organisation and of the International Labour Organization

The WHO and the ILO contributed to a wide extent to the debate on long-term care by providing both strong policy recommendations and relevant data enabling policy makers to adopt evidence-based measures enabling older persons to exercise their rights.

The World Health organization (WHO)

Within the UN, WHO is the directing and coordinating authority on international health, by leading international processes in the area, shaping the research agenda, setting

norms and standards, provide technical support and building the capacity of the governments involved.

According to the WHO, “health” is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

The WHO’s activities in the field of ageing are numerous. Three main areas of interest on the rights of older persons in need of care are the following:

- **Age-friendly cities framework**



According to the WHO, “a key strategy to facilitate the inclusion of older persons is to make our world more age-friendly. An age-friendly world enables people of all ages to actively participate in community activities and treats everyone with respect, regardless of their age. It is a place that makes it easy for older people to stay connected to people that are important to them. And it helps people stay healthy and active even at the oldest ages and provides appropriate support to those who can no longer look after themselves”.

A label and a **guide for "age-friendly cities"** have been developed since 2007, and **a dedicated website, called Towards an age-friendly world** has been made available.

- **WHO Strategy and action plan for healthy ageing in Europe (2012-2020)**

WHO is actively involved in designing the international policy framework in the field of healthy ageing, which impacts on many aspects of the lives of older persons in need of care.

The Strategy has a dedicated part on ‘People centred health and long-term care systems fit for ageing populations’, and includes specific interventions on informal care, prevention of elder maltreatment and ‘Quality of care strategies for older people

including dementia care and palliative care for long-term care patients'. [Look at the strategy for more information.](#)

- **The WHO European region report on preventing elder maltreatment**

This report is a unique reference document on elder abuse, analyzing existing data on elder abuse and providing overall analysis and policy recommendations for governments. [The report is available here for download.](#)

The International Labour Organization (ILO)

The ILO is a UN organization giving an equal voice to workers, employers and governments to ensure that the views of the social partners are closely reflected in labour standards and in shaping policies and programmes.

The main aims of the ILO are to promote rights at work, encourage decent employment opportunities, enhance social protection and strengthen dialogue on work-related issues.

It regularly publishes reports and recommendations for governments, including in the field of quality of work for care practitioners, and social protection.

It published in 2015 a **study on long-term care protection for older persons** which highlights the fact that more than half of the global population aged 65 and above, representing 300 million people, is excluded from urgently needed long-term care (LTC), partly due to a lack of 13.6 million LTC workers worldwide. The report states that LTC needs to be an integral part of any comprehensive social protection system. It includes also information on the European region, highlighting gaps in access to quality care and availability of care professionals.

MORE INFORMATION:

- [ILO study on long-term care protection for older persons.](#)

Conclusion Part 1

At international level, various instruments take into consideration the rights of older persons as previously seen. These instruments and processes aim at providing useful guidance for policy and practice in long-term care.

While most of these are not binding for national governments, they allow national governments and the EU a wide margin of appreciation as to how far they will apply the principles to which they have committed. Few effective monitoring mechanisms are also in place to assess progress at all levels.

Lacking adequate tools and comprehensive national policy frameworks which help them deal with the numerous policy objectives and international standards, it can be very difficult for practitioners to implement a rights-based approach in their work.

As far as the binding legal instruments are concerned, such as the UN Convention on the Rights of Persons with Disabilities and the European Convention of Human Rights, so far these have only paid marginal attention to the specific challenges faced by older persons in need of care.

This is why various organisations, including AGE Platform Europe, are arguing in favour of **a new comprehensive legally binding UN treaty that would harmonise the application of these shared principles** and provide for a monitoring framework enhancing governments accountability for the provision of quality rights-based long-term care.

MORE INFORMATION:

- [AGE's handbook on the rights of older persons](#)

Part 2:

The rights of older persons in need of care and support at EU level

PRELIMINARY REMARK

The European Union can play a key role in supporting the rights of older persons. Several EU initiatives, policies and directives directly or indirectly target older persons in need of care.

AGE Platform Europe developed a brochure called 'Active Senior Citizens for Europe, a guide to the EU' which summarizes the main policies and processes impacting older persons' rights at EU level. The brochure is summarized in [a short guide to the EU, translated into several languages](#).

EU policies and legislation

The responsibility for health and social care provision lies with Member States. However, the EU has several tools that it can use to support and promote the rights of older persons in need of care.

A key provision for older persons in need of care is Art. 25 of the European Charter of fundamental rights, which states the following:

“The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life.”

According to this article, EU institutions should not adopt legislation that goes against the rights of older persons. However, this does not mean that they are free to take any action to promote this right, as they have to respect the competencies of national governments. Moreover, this article is not binding upon national governments, unless they are implementing EU law.

Areas in which the EU has competence to act are:

- Gender equality, including through action to better balance care and work responsibilities; violence and abuse
- Non-discrimination on the basis of age and/or disability, including dedicated legislation to tackle discrimination in employment
- Health promotion
- The protection of consumers and victims through the application of common standards



As mentioned above, the EU also ratified the UN Convention on the rights of persons with disabilities.

Finally, the EU supports the exchange of practices and national policy reforms in the field of pensions, health and long-term care.

The main processes that are relevant for older persons in need of care are the following:

- **Non-discrimination** in the field of disability, applied through the Disability strategy 2010 – 2020 and the implementation of the UN Convention on the rights of persons with disabilities.

The EU has singled out older persons in need of care as one of the key target groups of these two instruments. Nevertheless, it has not given any further guidance on how the principles and guidelines enshrined therein apply to the specific challenges of older persons with functional limitations, nor has it addressed age barriers in disability benefits.

- **Social policy and social protection**

The EU supports governments in exchanging practices and in applying policy reforms. This is the case in the field of pensions, and in the field of health and

long-term care. The following processes are of specific relevance for the field of long-term care:

- **The European Semester**, which is a cycle of economic coordination where proposals for policy reforms are made after exchanges between the European Commission and the governments. Each year, AGE Platform Europe publishes an analysis of the country reports on the basis of the realities faced by older persons in each country.
- The European Union has developed rules for **Social Security coordination**, in order to clarify which national rules and social security regime applies in cross-border situations (employees working in a country other than their own, retired persons living abroad, etc.) and to frame portability rights (meaning the ability to access the benefits of the country of origin in another European Union country). This includes benefits in cash and in-kind (services) for long-term care needs. The new legislation on social security coordination proposed by the European Commission **mentions for the first time explicitly long-term care benefits**, and sets a common definition of these benefits, criteria to identify them and a list of benefits in each European Union country.
- The **European Pillar of Social Rights** was launched in 2016 by the European Commission through a consultation. The document presenting the overall idea included, among the 20 social rights identified, the right to long-term care. By the last update of this toolkit, the final form that the Pillar would adopt was unclear and to what extent it would be mainstreamed and enforced across European Commission's policies.
- **The activities of the Social Protection Committee (SPC)**, a group of representatives from national ministries exchanging practices and proposing policy actions.

- **Health**

The EU has a two-fold role in the field of health. First role lies in the regulation of medicines and healthcare professions, and second in the promotion of health and healthy lifestyles. Three main areas are of interest for older persons in need of care:

- EU action for **the rights of patients in accessing healthcare in another EU country**: in 2011 the Directive (form of EU legislation) on patients' rights in cross border healthcare was adopted. This directive sets up common rules on access to healthcare in another country. However, the directive only applies to the field of healthcare, and explicitly mentions the fact that **it does not cover long-term care services** whose primary purpose is to support people in need of assistance in carrying out routine, everyday tasks.
- The activities of the **European Medicines Agency**, which set up a working group on geriatric medicines in which AGE Platform Europe is represented, and adopted a Geriatric medicines strategy. The Agency is mainly responsible for the evaluation of new medicines in the EU, including medicines for diseases affecting older people. The Agency also monitors the medicines available in the market.
- The EU adopted common frameworks and regulations on **healthcare practitioners** (nurses, pharmacists, dentists, etc.), which support some form of quality assurance across Europe. However, there is a lack of formal recognition of long-term care and palliative care professionals, and of the need to develop geriatric and gerontological skills across the EU. There are also policy debates on the growing number of workers in the field of 'personal and household services' and how to ensure their proper support and training.

- **Victims' rights**

In 2013 the EU adopted **a directive to protect and support victims of crime**. National governments had to transpose the directive by 16 November 2015.

The Directive aims to **guarantee access to adequate and quality services to all victims**, and support cooperation between different stakeholders, and the development of specialized victims support services. While elder abuse is not explicitly mentioned, the directive includes an article forbidding age discrimination and discrimination based on disability in accessing victim support services. In addition, specific provisions on violence in “close intimate relationships” and interagency cooperation can be used to tackle some aspects of elder abuse.

You can find more information in the website of **Victims Support Europe network** and read the **text of the Directive**.

- Last but not least, in 2008, the European Commission proposed a **directive to tackle discrimination in access to goods and services that would cover age discrimination**. This has since been negotiated by European Union countries, some of which block the adoption of the Directive. To date, only age discrimination in employment is forbidden. **More information here**.

The European Commission also supported the organization of several conferences and funded several EU-wide projects on long-term care and the fight against elder abuse.

The EU support help both to advance policy reflections across countries and develop concrete tools (trainings, policy frameworks, quality care indicators, etc.) to support the rights of older persons in need of care and assistance. The European Union funded two projects coordinated by AGE Platform Europe: the first one delivered the European Charter for the rights of older persons in need of care and assistance and the second

one the European Quality framework for long-term care. More information can be found in **Part 4**.

The European Commission allocates funding for projects aiming to combat violence on women, children and groups at risk, and to support the rights of victims. More information [here](#).

The role of national governments at EU level

National governments (and increasingly local governments in some countries) have the main competence concerning elder care services. However, they exchange practices and policy responses at EU level, shaping a shared position at EU level on how to address common challenges.

In this regard, **national governments agreed on general policy messages** through different Council decisions, showing a growing political commitment for the rights of older persons in need of care in all EU countries:

- **Guiding principles for active ageing and solidarity between generations** (6 November 2012): adopted on the occasion of the European Year 2012 on Active ageing and solidarity between generations, the guidelines are a set of policy responses to the challenges of ageing. Recognizing the important contribution made by older people to society, it covers three main areas: employment, participation to society and independent living. The third area is of particular relevance for older persons in need of care, as it supports the policy objective of 'Maximising autonomy in long-term care' and respect the dignity of older persons in need of care.
- The Council adopted also conclusions supporting action in the field:
 - on **"Healthy and dignified ageing"** which invites the Member States to make the issue of healthy and dignified ageing one of the priorities

for the coming years and asks the European Commission to develop an action plan which will promote dignity, health and quality of life for older persons (2009)

- On “**Active Ageing**”, asking Member States to “ensure that health and social services cooperate and focus more on health promotion, including early intervention, to facilitate active, autonomous and dignified ageing” (2010)
- On “**Healthy Ageing across the Lifecycle**” which invites Member States to adopt a preventive approach but also to develop personal assistance for older persons in need of care (2012)

The European Parliament

The European Parliament has played an important role in raising awareness of elder abuse. Several MEPs have strongly supported AGE Platform Europe in promoting the rights of older persons in need of care and assistance and keeping this key issue on the EU agenda through amending reports, asking questions to the European Commission or organizing events.

In [2010, the European Parliament resolution on long-term care for older people](#) was adopted. It calls on the European Commission to set up minimum standards for all contracts in the care sector, including minimum wages and to deliver a “Green Paper on elder abuse and safeguarding older people in the community and in all care settings”.

The European Parliament also plays a key role in the approval of the EU budget. Using its voting power, it ensured that ‘older people’ were included as a target group in EU-funded programmes, enabling a wide range of projects and initiatives to be financed in the field of the fight against elder abuse and on long-term care.

It also held several events and released several reports supporting the rights of older persons in need of care (for more information, please visit [AGE Platform Europe's website](#) and news).

Part 3:

Building a policy response to promote and support the rights of older persons in need of care at EU level

Parts 1 and 2 aim to provide an overview of current policies, strategies and legal instruments covering directly or indirectly the rights of older persons in need of care and support.

Part 3 aims to support concrete policy action to move forward for the wellbeing and dignity of older persons in need of care. It includes a general analysis of the different responses that have been introduced, and reminds readers about the realities faced by older persons in need of care. A policy in the field should first aim at producing positive outcomes on the target group; in that regard, it is essential to plan how to adequately enforce their rights in practice and promote their inclusion in society.

Realities faced by older persons in need of care

What often comes out of the debates is that **many older persons in need of care are not aware of their rights**, and have the feeling that, as they depend on others for care and support, they cannot or should not claim their rights.

We all have in mind situations where the rights of older persons in need of care have been overlooked: limitations to freedom of choice, absence of informed consent, discrimination in access to quality healthcare services and mental health support, limited possibilities for adequate support services, undervaluation of the person's needs, lack of opportunities for participation, etc. **However, these limitations may appear in many cases as a form of normality or fatality in our societies.**

When referring to older persons in need of care, one needs to include **all living settings**, whether they live in a residential care home, at home, or day or night care settings.

The notion of ‘structural abuse’

Such examples of limitations showcase a form of **generalised ageism** in society, and of discrimination targeting older persons, especially those in need of care and assistance.

This should not be accepted as it is a violation of the dignity of older persons and contradicts Article 25 of the EU Charter of fundamental rights, alongside other legal instruments.

This inherent ageism is what we call **structural abuse**: a regular and systematic underestimation of older persons as target group of actions and policies. Structural abuse means that older persons are not seen as rights holders but as ‘bed lockers’. This impacts not only the rights of older persons, but also the whole eldercare sector which is confronted with inappropriate funding, inadequate working conditions and training for carers and care managers, and a lack of positive recognition of their work and of the work done by informal carers.

The voice of older persons in need of care

To fight structural abuse we need to give a voice to older persons in need of care themselves, to care practitioners and to informal carers. Here are some testimonies, which of course show only part of the reality:

“I am not hungry, the only thing I would eat is the yoghurt but I can’t open it, so I leave it.”

“Don’t worry about those bruises, it must be because she doesn’t have a good balance and bumps into furniture.”

“What I miss is the freedom to choose, to choose when I get up, what to have for lunch, what to wear today.”

“I don’t understand why I have to take all these medications, they make me feel dizzy.”

“I don’t like being treated like a piece of furniture. Can’t they talk to me when they wash me instead of discussing between them what they did last weekend? I am not dead yet. I have feelings too!”

“It took me three years as a child to learn not to wet my bed at night and now they want me to do it again because they don’t have time to come and help me to the toilet at night!”

“I can’t cope anymore and need to find a solution for my father (with severe Alzheimer) but I can’t find the information I need about what is available. I spent hours on the phone and I still don’t know what to do.”

“When my wife died, I felt really hopeless and isolated. I didn’t know how to cook a proper meal, yet I didn’t want to call for the meals-on-wheels. The lady from the community service encouraged me to join their cooking class for seniors and here I am. At 93, I am enjoying every moment of it! I have made new friends and we have fun together.”

“I don’t understand how it is still possible today to let people develop such bedsores!”

“I love him but I couldn’t stand his screams anymore and I slapped him. Now I feel miserable.”

“When I tried to report elder abuse to my line manager, the next day I received a letter from the Director telling me that I was sacked for moral harassment of other staff.”

These testimonies come from the [European Charter for the rights and responsibilities of older people in need of care and assistance, accompanying guide, 2010.](#)

A report was developed by the UK Equality and Human rights commission, entitled *Close to home - An inquiry into older people and human rights in home care*. It is based on interviews and further research made with older persons receiving care services at home. As stated on the key findings posted on their website, the report shows that ‘Around half of the older people, friends and family members who gave evidence to the inquiry expressed real satisfaction with their home care. At the same time the evidence revealed **many instances of care that raised real concerns such as:**

- Older people not being given adequate support to eat and drink (in particular those with dementia) and an unfounded belief that health and safety restrictions prevent care workers preparing hot meals.
- Neglect due to tasks in the care package not being carried out, often caused by lack of time.
- Financial abuse, for example money being systematically stolen over a period of time.
- Chronic disregard for older people’s privacy and dignity when carrying out intimate tasks.
- Talking over older people (sometimes on mobile phones) or patronising them.

- Little attention to older people's choices about how and when their home care is delivered.
- Risks to personal security, for example when care workers are frequently changed sometimes without warning.
- Some physical abuse, such as rough handling or using unnecessary physical force.
- Pervasive social isolation and loneliness experienced by many older people who lack support to get out and take part in community life.”

The same report already proposes some ideas for improvements and highlights some of the **barriers older persons face to talk about the breaches of their human rights**. These include: a reluctance to complain, a lack of active involvement in their care if no choice at all, lack of knowledge on quality standards applying, and over-reliance on self-assessment of quality by care professionals themselves, preventing a range of issues to be known at policy level or in civil society organisations.

MORE INFORMATION:

- The full report [can be found here.](#)

Elements of a policy response

Based on all the accumulated knowledge and experience from policy and practice in the field, **several key areas of action need to be considered for an efficient policy response** to the different challenges faced by older persons in need of care in their enjoyment of their human rights. These elements of policy response are the following:

- Develop an overarching framework on the rights of older persons

- Provide adequate social protection for long-term care needs
- Develop a rights-based approach to quality monitoring and control in eldercare services
- Prevent and fight elder abuse

Develop an overarching framework on the rights of older persons

This overarching framework should first and foremost see older persons, including those receiving care and assistance, as a resource for society, on an equal footing with all other age groups. This framework would offer a more targeted approach to older persons and make their contribution to society and the challenges they face visible. It should provide a much clearer and adapted response to their day to day realities.

Indeed, whereas older people do not have special rights, older people in care settings face specific barriers to enjoying their human rights, this is why we have to define how their rights can be effectively realised in the context of ageing. It is important to bear in mind that older persons with care needs **often do not identify themselves as persons with disabilities**, nor were they involved in the drafting of the United Nations Convention for the Rights of Persons with Disabilities (UNCRPD).

Concretely, this means that **at UN level, a new convention on the rights of older persons should be developed**. The need for a convention is currently debated, and especially in the framework of the Open-ended working group on ageing (see [Part 1](#)). Most EU countries are so far against such new instrument, as it would potentially impose new obligations, but number of UN Member States consider this option as the most efficient way to recognize and enforce the rights of older persons in the world.

Some countries did not wait for a UN convention to start the work. In 2015, the [first Inter-American Convention on Protecting the Human Rights of Older Persons was](#)

adopted which is the first binding instrument addressing the rights of this group.. AGE members decided to support a UN Convention for the rights of older persons, which would cover as well older persons in need of care and support. More information on AGE's position is available [here](#).

At EU level, a coordination of all policies on demographic change and ageing should be developed, for example through a **European Strategy on demographic change**, as proposed by AGE Platform Europe. This coherence, under a common vision for positive ageing, should apply to all fields of the work of the European Commission: Justice, Employment and Social affairs, Internal market and economy, Health, Digital market, Migration, etc. It would need to be applied in a **transversal manner to all of the [10 points of President Juncker](#)**, which are the main priorities for the current European Commission.

Such overarching frameworks should also **support participatory approach methodologies**. These approaches of co-design of policies should involve a wide range of stakeholders, starting with older persons themselves. The innovative solutions that need to be developed indeed call for experimental approaches and action groups to deliver results in that field. These participatory approaches should also make sure they reach older persons in need of care. [An example of guidelines is available here](#)

Provide adequate social protection for long-term care needs



How to ensure at EU level an effective and coordinated social protection for long-term care? This is currently an open debate, supported at EU level by exchange of experiences and responses between national governments in order to raise common issues.

The Social Protection Committee developed together with the European Commission a **report on Adequate social protection for long-term care needs** addressing what they identify as key common challenges across countries:

- the growing demand for care
- the lack of carers
- the quality challenge
- the financial challenge

The report provides proposals for policy response such as:

- deployment of a prevention and rehabilitation approach
- development of integrated care and of age-friendly environments
- use of technology
- support to informal carers

The report includes finally a short analysis per country.

While AGE welcomed the report, we highlighted several actions that need to be developed to enable a concrete step forward for the rights of older persons in need of care, so that the report does not remain a tiger paper:

- Monitor the impact of cost reduction measures through a human rights, social and health assessment in all Member States
- Support the development and monitor the quality of long-term care provision in the EU
- Adopt an EU action plan against elder abuse
- Involve and support stakeholders' cooperation at all levels to strengthen the implementation of the existing legislation and policies

AGE reaction includes **a detailed explanation for each of the four points.**

During AGE's General Assembly in 2014, the European Commission also addressed **several questions aiming to advance reflection in the area:**

- **What is the right model for social protection against long-term care (LTC) needs?**

What would be the respective roles of individuals (as potential users of LTC), families and the state in that regards?

AGE members support universal access to social protection, and a **full recognition of long-term care as a right and an inherent risk in life**, with the development of relevant investments and support needed to make this right a reality. Without this support available, older persons' dignity is at stake. Firstly, ensuring that older persons in need of care can exercise their 'right to health' and 'independent living' is crucial. Moreover, enshrining a specific 'right to long-term care' means addressing the persisting **inequalities** faced by older people in accessing care services, which may depend on geographical area or social class. Recent austerity-driven policy reforms have widen existing inequalities; long-term care has become in many countries an adjustment variable for public spending, which has seriously limited coverage and access to adequate protection.

While the role of informal carers should be recognized and supported, AGE members are convinced that the development and investment in quality formal care services, which allow choice for the older person over a range of person-centred services, should be privileged. Choice also means that informal carers should be able to choose and not be forced to provide care and that they can do so in a supportive environment in cooperation with a network of qualified professionals.

- **How can we best support and include those who want to take care of relatives into the provision of LTC?**

It is indeed important not to discourage or penalize informal carers.

Whereas AGE members do not have a position on whether to privilege in-kind or in-cash support to informal carers, it is clear that choice should be the main approach taken to develop policies. This means that a flexible range of different services, from information to training, to cooperation with day care or night care centers, and with specialist organisations such as Alzheimer centers, and recognition of skills acquired, should be favoured. Information on such services should also be disseminated.

- **To what extent should we expect individuals to use their own income and assets to pay for LTC?**

Indeed, we have to protect partners, but what about the children or other heirs' financial responsibility?

AGE members have a strong position on the fact that **needing long-term care should not lead to poverty**, and that dignity should be protected. In many countries, the cost for long-term care is often high, part of which is sometimes covered by State support. Experience from AGE members also showed that exclusively relying on the use of the older persons' assets is not a sustainable solution, which may lead to difficult situations once the amount of the assets is spent, as well as higher inequalities among the older population. Long-term care private insurances are often inadequate to cover different needs, and especially high care needs. It is believed that, while long-term care is certainly a cost, more should be done to enable persons needing long-term care to live autonomously and include them in society, reducing healthcare and social support needs, and better allocating funding for those with high care needs. This includes the development of age-friendly environments.

- **Which services, and which quality, should be guaranteed?**
Regardless of who (individuals, families, state) has the primary responsibility for LTC

AGE developed, together with other partners, a **European Quality framework for long-term care services** (2012) which aims to define what means quality care and provide several quality principles shared at European level.

These highly relevant questions should be debated at all levels, including when reforming or developing national policies on long-term care. AGE members currently work to provide more inputs to these different questions.

Develop a rights-based approach to quality monitoring and control in eldercare services

How to ensure all over the EU, that older persons in need of care receive quality long-term care? This is one of the questions also debated at EU level, and in particular on how quality assurance mechanisms can be put in place to support the wellbeing and dignity of older persons in need of care.

So far, the EU did not regulate the question of quality services in the field of long-term care. The Social Protection Committee released a **Voluntary quality framework for social services**, which outlines quality principles that social services should follow. However, this is neither binding nor is its implementation monitored.

With the rising number of cross border care service providers, and the absence of regulation on quality elder care in some EU countries, the need for a strong quality framework at European level has become a necessity. This is the goal of the work done by AGE in the **WeDO project**.

In addition, more information on how quality is currently monitored and controlled in the different European Countries should be gathered by national governments, from the point of view of older persons in need of care.

In general, **very limited evaluation and data is gathered on the realities lived by older persons in the EU**, and especially by older persons in need of care, the discriminations they face, and the types of ageism they suffer from. Many interviews are exclusively ‘satisfaction questionnaires’ or interviews, and there is a lack of support to older persons’ organisations in many countries to gather such information, and in particular on the situation of older persons in need of care.

National and local authorities and practitioners could for example report on the way they apply instrument instruments such as the UN Convention on the rights of persons with disabilities to older persons in need of care.

They could also support similar projects as the one coordinated [by the European Network for Human rights institutes on older persons in long-term care facilities](#).

Prevent and fight elder abuse

Elder abuse remains largely a hidden problem, both in statistics and policies; the development and implementation of a **coherent policy to address it through a rights-based quality long-term care system**, is highly and urgently needed. For example, there is no EU strategy to combat elder abuse.

During an event co-organised in **June 2015 by the Council of Europe, the European Commission, AGE and ENNHRI** in Brussels a **framework for an efficient strategy on elder abuse** was introduced by Mrs. Silvia Perel-Levin. Her presentation included the different areas for such a strategy:

- Data collection
- Prevention
- Detection

- Intervention
- Training

She detailed each part of the [strategy in her presentation, available here](#).

Measures to fight against elder abuse should be implemented and address all types of maltreatment. For example, **financial abuse is not efficiently addressed**. More needs to be done to analyse and tackle for example the financial exploitation of older people in consumer and private relations. Besides, pharmaceutical abuse is also not adequately addressed.

The [event around the World Elder Abuse Awareness day co-organised by AGE in June 2016](#) highlighted situations of abuse that happen in health and long-term care, either at home or in residential settings. Speakers identified the lack of awareness of care professionals and informal carers as one of the key factors behind the prevalence of abuse and neglect. Ageist attitudes in some health and social care professionals are often a subtle form of neglect that can have a serious impact on the wellbeing and sense of dignity of older persons.

Specific and targeted trainings to raise awareness of the right of older people to dignity and how this can be enforced in daily caregiving was consistently highlighted as necessary means to prevent abuse. Speakers highlighted how interactive trainings are much more effective than brochures and booklets, and stressed the importance of improving the working conditions of health and social care professionals.

AGE works to highlight the realities reported by our network members, and has developed several policy recommendations to reinforce the rights of older persons in need of care in the EU. Our work in the field is updated regularly [on our website](#).

Some ideas for actions that can be taken by policy makers and practitioners on a short term

Apart from seeking to elaborate comprehensive policy responses as previously described, we identify **two main actions** that, in the short run, could encourage a wide range of stakeholders to work together on common solutions and actions based on a shared vision.

First, to provide funding or take part in multi-stakeholders projects in this field, promoting a rights-based approach to care.

As an example, the European Commission funded the European Network of Human Rights Institutions (ENNHRI) to **coordinate a project aiming to improve the human rights protection of older persons in long-term care**, with particular emphasis on residential care. The project specifically seeks to introduce a human rights based approach to long-term care of older persons, and to increase awareness of the human rights of older persons living in or seeking access to long-term care in Europe. .

The ENNHRI project on older persons aims at:

- Describing the human rights situation of older persons in care in Europe
- Introducing a human-rights based approach to the long-term care sector
- Supporting National Human Rights Institutions to carry out monitoring work in LTC, and increase recognition of their role.

The project has delivered an overview of human rights instruments relevant to the rights of older persons in need of care, an overview of the experiences and initiatives taken by National human rights institutes in that field, and some guidelines for the monitoring of human rights in long-term care facilities. The findings of the project reveal that older

persons are confronted to violations of their human rights, which is often due to the lack of awareness of care managers and professionals.

The final findings of the ENNHRI project can be found [here](#).

Second, to support the **organisation of events and workshops**. This is what for example AGE Platform Europe is doing on an annual basis in collaboration with the European Commission, the Council of Europe and other key stakeholder, **to mark the World elder abuse awareness day (15 June)**.

These annual events are an excellent opportunity to share current policies and practices, offer open debates and share experiences from a wide range of organisations and individuals, especially those who are not used to working together.

In 2014, the event aimed to build linkages between the work of the European Commission on social protection for long-term care needs, and the Council of Europe recommendation on the rights of older persons. In 2015, the event targeted the field of victims support and consumers rights, and sought to highlight whether current international instruments addressed adequately the rights of older persons. In 2016, we explored the situations of abuse and violations of rights that may take place in health and long-term care, including those suffered by older women and older migrants, in order to highlight the need for a rights-based approach to care.

These events help to build linkages and gain knowledge and understanding on the different legal frameworks and grassroots initiatives supporting the rights of older persons in need of care and assistance. Proposing concrete action, and drawing from the expertise of stakeholders from different countries working in the field of human rights, social and healthcare or justice and at different level, these events steered policy action at all levels. They finally aimed to echo current debates at UN level around a new convention on the rights of older persons.

Part 4:

Wellbeing and dignity for older persons in need of care: a toolbox

A wide range of tools and solutions are available and part of them are shared here to show both that it is possible to adopt a rights-based approach to care and that there exist concrete ideas and even already concrete tools that policy makers and practitioners can use to move forward.

In particular, this part summarizes a package of tools developed by AGE Platform Europe together with more than 200 organisations in Europe from 2008 to 2015. These tools are complementary and all aim to raise awareness on a common vision and enforce in practice the rights of older persons in need of care and improve quality of care.

All these projects' results were used to influence the various instruments described in Part 1 and 2: the Council of Europe recommendation on the rights of older persons, the UN processes and most of the EU ongoing activities in the field. These projects have influenced legislation or practice in 15 EU Member States, as shown in the next pages.

The European Charter for the rights and responsibilities of older people in need of care and assistance

The EUSTaCEA project (2008-2010 funded by the Daphne programme) developed a **European Charter for the rights and responsibilities of older people in need of care and assistance**. The Charter aims to clarify what are the rights of older people in need of care, and increase understanding of older people as rights holders, including among older persons themselves. It emphasizes the fact that a lack of autonomy does not mean a loss of rights:

“As you grow older and may come to depend on others for support and care, you continue to have the right to...”

It includes 10 articles, 9 rights and one article on responsibilities:

- Art. 1: Right to dignity, physical and mental well-being, freedom and security
- Art. 2: Right to self-determination
- Art.3: Right to privacy
- Art. 4: Right to high quality and tailored care
- Art. 5: Right to personalized information, advice and consent
- Art. 6: Right to continued communication, participation in society and cultural activity
- Art. 7: Right to freedom of expression and freedom of thought/conscience: beliefs, culture and religion
- Art. 8: Right to palliative care and support, and respect and dignity in dying and in death
- Art. 9: Right to redress
- Art. 10: Your responsibilities

It is translated into Catalan, Czech, Dutch, English, French, German, Greek, Italian, Polish, Romanian, Slovenian, Spanish, Swedish, and you can find it [here](#). This Charter is supported by an ‘**Accompanying guide**’ addressing each of the rights expressed in the Charter, explaining what they concretely mean and how they can be enforced.

The guide contains: testimonies from older people, recommendations to different groups of people and professionals (policy makers, informal carers, service providers, older people themselves) as well as examples for good practices. It also provides a checklist.

FOR MORE INFORMATION:

- **The full text of the Charter and its accompanying guide can be downloaded on [AGE Platform Europe website](#).**

The European Quality framework for long-term care services

The WeDO project (2010-2012 funded by the Directorate-General for Employment, Social Affairs and Inclusion of the European Commission) is based on the Charter and created a European partnership for the wellbeing and dignity of older people.

The project involved more than 200 organisations in 12 countries in Europe, including public authorities, service providers and organisations of older people. Together they reflected on what quality of services means, and drafted a **European Quality Framework for long-term care**.

The framework was developed thanks to a multi-stakeholders participatory approach. The quality framework is based on quality principles (what a quality service is) and areas of action (what a quality service should contribute to). You will find them in the next page.

The Quality framework is available in English, English (version for Ireland), French, German, Italian, Dutch (version for Netherlands), Dutch (version for Belgium), Swedish, Finnish, Slovene, Czech, Greek, Spanish (translation and edition done on a volunteer basis by FATEC) and Polish (translation on a volunteer basis by the Foundation for Women's issues in Poland).

Quality principles

- Respectful of human rights and dignity
- Person-centred
- Preventive and rehabilitative
- Available
- Accessible
- Affordable
- Comprehensive
- Continuous
- Outcome-oriented and evidence based
- Transparent
- Gender and culture sensitive

Areas of action

- Preventing and fighting elder abuse and neglect
- Ensuring good working conditions and working environment and investing in human capital
- Empowering older people in need of care and create opportunities for participation
- Developing adequate physical infrastructure
- Developing a partnership approach
Developing a system of good governance
- Developing an adequate communication and awareness raising

FOR MORE INFORMATION:

The full version of the Quality framework in all languages [is available here](#).

The Quality care training package

From 2013 to 2015, a partnership of organisations called WeDO2 made a step further by developing a European **Quality care training package**.

This package aims to inform people (including care professionals, volunteers, policy makers and younger generations) on the Charter and on WeDO, and foster reflections on what 'good care' concretely means .

In total, the WeDO documents are available now in 14 languages and used in 15 countries of the European Union, while its outreach is expected to grow in the upcoming years.

[Access the training package here.](#)

Enforcing the Charter and WeDO in the different European countries

Representatives of the WeDO partnership regularly meet to exchange experiences. They keep the [WeDO partnership website](#) updated.

To see more information, click on the country name and you will be redirected to the country webpage.

Austria

- The Ministry facilitated the organisation of train-the-trainer programmes on the WeDO quality care training package in each of the 9 Austrian regions, with the support of the organization ProSenectute.
- Both the charter and the quality framework influenced the elaboration of checklists for quality care targeting different groups of professionals, developed by the Austrian Red Cross.
- The Styx region and several other regions are also using the WeDO framework to monitor the quality of the eldercare services in their region.
- Austrian activities in WeDO can be followed on a specific website here: <https://wedo2austria.wordpress.com/>.

Belgium

- The WeDO quality framework was endorsed by five regional ministers in Belgium.
- The Vrije Universiteit Brussels included the Quality care training package in several of its training programmes, and regularly delivers conferences on the topic.
- Organisations committed to WeDO meet regularly to exchange experiences and practices, especially between francophone and Flemish speaking organisations. They organised several high level events involving different ministries, to foster cooperation and understanding of the issue.

- WeDO is also used as a reference document to measure quality in the biggest care organization in the Flanders.

Czech Republic

- The organization Zivot90 is running a helpline for victims of elder abuse, and is involved in several expert groups at national level. They continue to raise awareness on the Charter of Rights and WeDO quality framework.

Finland

- The WeDO project was a unique opportunity to gather a wide range of stakeholders around the table and bring a comprehensive approach
- The Charter and WeDO influenced a new law on social and health services for older people, with principles of participation and diversity much more emphasized
- WeDO also influences trainings of care managers.

France

- The Quality framework influenced the work of the main organization of social service providers in France, and continue to be a reference document disseminated to all local social care centres.

Germany

- The Charter of Rights and WeDO quality framework influenced the revised version of a widely used quality assessment tool :
<http://www.heimverzeichnis.de/>.

Greece

- The WeDO project was a unique opportunity to gather a wide range of stakeholders around the table and bring a comprehensive approach. The

coalition continues to meet regularly and decide on common actions to be taken

- The WeDO coalition influenced the national Alzheimer Plan, and also drafted together an Action Plan on ageing for Greece
- The Quality care training package will be used in the training curriculum of psychologists, and an organization of social workers is interested to use the training as well.

Ireland

- The Secretary of State officially endorsed the WeDO quality framework
- The organization Age&Opportunity is currently working to use the WeDO framework to advise the creation of a new and innovative residential care home

Italy

- The Quality framework was an inspiration for several European and local projects on combating elder abuse and supporting an integrated approach to care.

The Netherlands

- WeDO led to the publication of a [report on the quality of long-term care services](#) by the Dutch coalition
- The quality care training package is now part of the work of the main association of care recipients, LOC. This organization will now increase its work on ethics and human rights in care.

Poland

- Organisations of older persons were actively involved in designing the Polish Action plan on ageing. They are now launching a coalition of organizations specifically on the rights of older persons in need of care

- The Quality care training is now used in several cities to support intergenerational cooperation, and in particular in schools

Slovenia

- WeDO and the Charter are now reference documents for all care services contracts in the care services.
- This process is supported by the Ministry of labour, family, social affairs and equal opportunities.

Spain

- The Charter and the WeDO framework are used as a reference to assess quality of care in some care homes in Catalonia. This activity is done by trained volunteers and is called '[the care home I would like to live in](#)'.

Sweden

- Organisations committed to WeDO launched a campaign '[Elder abuse does not retire!](#)'.
- After that, the government adopted a Strategy to prevent elder abuse.
- These organisations also influenced, using WeDO, a national standard on quality of care for older people

UK

- A [detailed report on human rights in home care](#) used the Charter as a reference by the Equality and human rights commission
- A local coalition will continue to meet in Slough and Berkshire East, run by Age concern, after the success of the WeDO2 final conferences
- The Quality care training package is part of the activities of the organisation

Resources

Additional resources can be found on AGE website's [section on dignified ageing](#).

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