The EU Care Strategy must be built on supporting all human rights

AGE Platform Europe response to the Commission call for evidence on the European Care Strategy

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Summary

Introduction

According to the Social Protection Committee's 2021 Report on Long-Term Care, Europe will face an increase of the number of persons in need for care and support to 130 million by 2050, a rise o by 41%. The Social Protection Committee also underlines the extent of unmet care needs. About one in three persons in need for care and support in the EU is not able to access formal care, while the care needs of persons with lower incomes are more often higher than for persons with higher incomes.

There is a strong gender dimension to unmet care needs, as about 37% of women over 65 report needs for long-term care, versus 23% of men 65+. Women live 3.5 years longer than men on average and spend 12.7 years with a chronic health condition or disability, compared to 9.2 years for men.

The pandemic has brought to light a broad lack of esteem for the long-term care sector, as more than half of fatalities due to COVID-19 took place in long-term care settings, with reports of lack of protection for cared-for persons and staff, denial of medical treatment to confirmed or suspected cases of severe infections and blanket rules effectively leading to social isolation, loneliness and the related decrease in mental and physical health in older persons in need for care and support. Fatalities and issues related to home care have unfortunately not yet been researched in this context.

After the adoption of the European Pillar of Social Rights (EPSR) in 2017 and its relating Action Plan in 2021, the European institutions have not operationalized the right to long-term care, provided for in article 18 of the EPSR, as the Action Plan was released at the same moment as the reflection process on the Green Paper on Ageing. The EU has ratified the UN Convention on the Rights of Persons with Disabilities, which requires to protect and promote the rights of persons of all ages with disabilities, which has a major impact on the perspective the EU should take on long-term care. Particularly the aspect of choice over the type and place of care they receive is part of the Convention.

Against this background, **AGE welcomes the announcement of the EU Care Strategy** and has high hopes that it forms the starting point of not only formulating a necessary policy in the light of the demographic and economic considerations linked to long-term care, but triggers also change in accordance with the ambitions of the EU to be a global leader on values. The EU can thereby also contribute to the Sustainable Development Goals (SDG 3) and the United Nations Decade on Healthy Ageing.

AGE has led a reflection process about our vision of long-term care, to ensure it is truly rights-based and adapted to the context of advancing longevity, setting out a policy brief with the result of these

reflections. We also contributed our vision on long-term care to the consultations on reinforcing social Europe and on the Green Paper on Ageing.

1. Taking a rights-based-approach to long-term care

We emphasized in our various contributions that EU policy in the field of long-term care has to take a rights-based approach. This is the only conclusion from the wording in the EU Charter on Fundamental Rights (art. 25), but also the principle 18 in the European Pillar of Social Rights. We emphasized that the right to long-term care needs to support the right to inclusion of persons with disabilities (principle 17), extending support to income support and services to allow participation in society. In the case of care, the Strategy **should emphasise the aim of care services and support: the right to live in dignity and independence and to participate in social and cultural life** (CFREU art. 25, as well as art. 26 on persons with disabilities). A rights-based approach means to build on the **participation of the persons concerned**, her or his consent and needs.

The starting point of **an individual right to long-term care** translates into a collective responsibility to ensure its provision. Too often, care is relegated by default on the shoulders of informal carers because of the lack of quality, affordable services. Too often as well, the person in need for care must comply with the conditions of care provisions (often leaving no choice but to go into an institution; sometimes however also at the contrary, obliging it to stay at home in situations of social isolation or without the support required to live in dignity in one's own home). An individual right to long-term care means that it should be provided **without discrimination of any kind**, such as in terms of gender, sexual orientation, identity, place of residence, income, age etc. Particularly, AGE wants to stress that older persons with disabilities should be able to access the same care services as all persons with disabilities. The Commission has set itself the aim to take a life-span approach in the EU Care Strategy, which means that it should not create artificial age-related boundaries in setting out the Strategy.

Taking a rights-based approach also **means to investigate and address situations where care is not (sufficiently) provided**, such as in sparsely populated areas or for conditions that are difficult to support. It means tailoring care to the needs of the individual in need for care. It means **not to limit the ambition of care to support persons for 'as long as possible'**, but to provide care wherever it is needed (and demanded) by the person in need for care. This translates the principle of progressive realization underpinning all social human rights.

The development of the EU framework on long-term care at this very moment in time should apply the principles set forth by the **World Health Organisation in its Framework** to support countries achieving an integrated continuum of long-term care, which has just been finalised.

Finally, the EU Care Strategy should **avoid language which disenfranchises persons** in need for care and support, such as by using 'dependent person' when the aim is to support independence and autonomy.

Finally, taking a rights-based approach means that care **must ensure that all other rights are protected and promoted** in the face of challenges to one's autonomy. This means connecting the right to care to other rights that are routinely challenged in the context of care: physical integrity, health, mobility, participation in social and cultural life, education and life-long learning, political participation etc.

Recommendations:

- Build the EU Care Strategy around the individual right to long-term care
- Emphasise the principle of non-discrimination in long-term care and disability inclusion services, specifically based on age
- Explicitly put the Strategy in the framework of the EU Disability Rights Strategy, the WHO Framework on Long-Term Care and all other rights in the CFEU and EPSR
- Put particular attention in the investigation of gaps in care provision and lack of choice in the forms of care, and directing funding and recommendations to close them

2. Choice as a fundamental element of the right to long-term care

Choice should be central in the provision of long-term care. Choice means first and foremost the informed choice to receive care and support or not. Choice means to choose the form of care one prefers to receive, such as home care, community-based or residential care.

Choice can only be made when different forms of care are available and affordable to the person in need for care.

Choice should also extend to informal carers. The lack of affordable, quality care services in many parts of the EU means that family members, friends or neighbours do not have the choice to provide care or not, leading to situations of overburdening, loss of income, challenges to mental and physical health or even to cases of abuse and neglect. The availability and affordability of care services should therefore be central to the EU Care Strategy.

This also means that care provision must find solutions for more challenging choices, such as the choice of a couple to continue living together despite different intensity of care needs for one or the other.

Recommendations:

- Make the development of all forms of care, especially home and community-based care a cornerstone of the Strategy
- Study and understand the dynamics of demand for different types of care and how this relates to the types of services offered. Prioritise investment into the types of services where demand from persons in need for care outweighs availability, to increase the choice of services available (e.g. home support, personal assistance).
- Use investments to reduce the out-of pocket cost persons in need for care have to provide, to ensure also persons with low incomes/wealth have access to choice.

3. Social protection approach to long-term care

To ensure the effectiveness of an individual right to long-term care, it needs to be affordable. While the need for care is made more or less likely relative to different socio-demographic factors (working conditions, living conditions, environment, food and other healthy living habits, education, social inclusion etc.), the randomness of care needs does not justify that individuals or their families have to stem the costs of care.

Recommendations:

- The EU Care Strategy **should encourage member States to establish long-term care as a branch of social protection**, with collective solidarity to provide the funding for long-term care. Spreading the costs of care on the shoulders of collective solidarity is also the only sustainable way to ensure funding and investment to meet increasing care needs.
- The EU Care Strategy should **assess the costs of long-term care to individuals** in a regular reporting framework and foster exchange of good practices to reduce it.

AGE also believes that a social protection approach – i.e. financing the care needs of the individual – is a good way to encourage care providers – public, private and not-for profit - to direct investments into areas where care is needed.

Long-term care is already defined in international law as part of the right to health (cf. ILO Convention 102 on Social Security (minimum standards).

4. Long-term care as a setting to live and strive

Long-term care settings can be very limiting to the individual's participation in social and cultural life. The climax of this has been observed during the height COVID19 pandemic, when many care homes were not provided with access to medical and emergency care and physical distancing measures were limiting the possibilities of persons in need for care to interact with one another

and with their friends and families outside.[1] This revealed an existing segregation between older persons in need for care and the rest of society. Many older persons in need for care had to pass away alone, lacking all kinds of support (emotional, spiritual, connection, …) during the pandemic, one of the most distressing aspects of this pandemic.

Recommendations:

- The EU Care Strategy should therefore not limit itself to the provision of long-term care in its direct understanding – services to support activities of daily living – but also **encourage social and cultural life in long-term care settings**. EU funds such as the Erasmus+ Adult Education strand, ESF+ and others can be used to improve participation of persons in need for care.
- The EU Care Strategy must be clear that the aim of care is to **maintain human contact** and social inclusion; therefore digitalization and robotization of care must not lead to a reduction of quality human contact of persons in need for care and support

5. Prevention of long-term care needs and their reinforcement

The European Commission has included 'prevention' into the aims to be tackled by the EU Care Strategy. Prevention of long-term care needs means that all public policies designing environments must contribute to reducing the onset of disabilities, frailty and chronic conditions. This fits perfectly into the declared UN Decade on Healthy Ageing, which includes actions to mainstream prevention into public policies, including for persons already in need for care and support.

Recommendations:

The EU should **commit in promoting age-friendly environments**, such as put forward by the World Health Organisation, defined as environments 'foster healthy and active ageing by building and maintaining intrinsic capacity across the life-course and enabling greater functional ability in someone with a given level of capacity'[2].

This means **integrating the prevention of chronic health conditions** by promoting healthy living through nutrition, activity, but also by designing environments, products and services to be accessible also to persons with disabilities and older persons.

More specifically, **prevention should also be part of a care pathway** of a person who has or will develop conditions that limit her autonomy. Physical activity, healthy nutrition and mental stimulation should be considered as services to be provided to persons in need for care

[1] Cf. for instance the reports on the EU country missions of Medecins sans frontières during COVID (Belgium, France, Spain, and the EU in general) and of Amnesty international on the first COVID wave in residential care settings in Belgium

[2] World Health Organisation, *Age-friendly environments in Europe. Indicators, monitoring and assessments*, 2018

6. Mainstream palliative care

AGE has participated in research projects that emphasise that palliative care is too often limited to the phase approaching the end of life. However, palliative care has a role to improve quality of life all along the pathway of a person diagnosed with a disability, long-term and/or possibly fatal condition.[3] Palliative care is often reduced to pain management, but has in fact a much larger scope, including psychological, psychosocial and spiritual support alongside medical care.

Recommendation:

The European Union has a role in promoting the mainstreaming of palliative care into long-term care and should highlight this need in the EU Care Strategy, making palliative care expressly part of an integrated continuum of care.

7. Support for informal carers

Currently, a majority of care needs are provided for by informal carers in the EU, often family members. To a large extent, these are older persons themselves, a large majority are women, and it has been analysed numerous times that informal care has a strong negative impact on the ability to continue working, secure income, mental and physical health. While increasing access, quality and affordability of formal care services is an important step to alleviate the burden for informal carers, there are specific actions the EU should take to directly support them. Indeed, even with more developed formal care services, informal carers have still an important role to play to support the well-being of persons in need for care, notably by supporting social participation, providing emotional care, human contact and belonging to a community. Often, informal carers are also the only persons coordinating the provision of health and long-term care services, as coordination mechanisms to ensure integrated care are lacking. Despite this, the informal carer is often not seen in her role in coordinating the services, and their needs for information, education about care, technical equipment and possibilities to cooperate with health and social care providers.

Still, it is not acceptable to rely on informal carers by default, providing care must be a voluntary act. Informal carers should

The EU has taken an important step by adopting the directive on work-life balance for parents and carers, which grants 4 days of leave per worker and year for informal care. For AGE, the directive has the main innovation of defining informal care in EU legislation and setting out the principle that it merits regulated absence from work. However, the directive has several shortcomings from the point of view of AGE:

[3] Cf. the outcomes of the EU FP7 project ''Comparing the effectiveness of palliative care for elderly people in long-term care facilities in Europe", PACE.

- Four days per year does not seem to be a sufficient amount off employment to coordinate health and long-term care services, let alone to provide emotional support
- The directive does not set out minimum standards for income security or social protection of informal carers
- Being a piece of labour market legislation, the directive does not include the provision of support services to informal carers

Recommendation:

The Council Recommendation on Long-Term Care should therefore include the following elements:

- Regular mapping of carers' leave arrangements and the provision of social rights (especially pension credits) in EU member States and encouragement to member States to go beyond the minimum provision in the directive;
- Work on a separate Council recommendation about social protection and services for carers
- Promotion of support services for informal carers: day-care and respite care services; training and peer counselling as well as personalized coaching. This support should take the form of available EU funding and the development of guidelines to member States for the support of informal carers

While AGE welcomes the transition towards more community-based care from the point of view of persons in need for care, AGE warns that this might mean placing a higher burden of responsibility on informal carers; therefore, informal carers must have an important place in the EU's Care Strategy

8. Investment and improving working conditions in long-term care

AGE has been calling several times, alongside disability organisations and trade unions[4], to improve working conditions in long-term care. High staff fluctuation, the high rate of temporary working contracts and the frequent complaints of staff about not having enough time to dedicate to persons in need for care and meeting their basic rights show that understaffing is reducing the quality of long-term care and its potential to improve quality of life of persons in need for care.

The recent scandals in France and other EU member States on the inadequacy, abuse and neglect in private care homes come as wake-up call that it is urgent to develop the quality of care. Inadequate care is not restricted to the private sector, but the possibility for the private sector to extract high profit margins at the expense of the human rights of the persons in need for care that trusted these

[4] See also the joint AGE-EDF-EPSU call to investigate the handling of COVID-19 in long-term care settings

providers shows that underinvestment, understaffing and lack of oversight have direct and negative consequences.

Recommendations:

AGE calls for the EU Care Strategy to:

- Encourage member States to further professionalise care roles by improving training for current and future workers in the sector. In particular, the prevention of elder abuse and the provisions of the UN Convention on the Rights to Persons with Disabilities and their applications in the care context should be part of the training of all care professionals.
- To promote effective social dialogue in the sector and at all levels, to increase pay and improve other working conditions for care staff
- Invest into the long-term care sector, also by means of EU funds and flexibility rules allowed for in the European economic governance framework, to stem the urgent and massive needs for investment and develop services that are ready to accommodate care needs across the EU.

9. Measuring quality and accessibility

A key component of the EU Care Strategy will be indicators and targets to improve accessibility and quality of care. AGE is conscious that it is difficult to define common indicators for such a varied field of different services, disabilities, health conditions, medical and social care needs and professions.

AGE does call for encouraging the access to long-term care by the setting of targets. To avoid the spread of low-quality care, access targets must be accompanied by quality targets.

Recommendation:

Long-term care has the overall task to maintain autonomy, independence, and well-being of persons in need for care and support. Therefore, indicators should be based on precisely these outcomes for person in need for care. AGE therefore favours indicators such as:

- Reporting unmet needs for care
- Increase of well-being of persons in need for care and support

Outcome-based indicators can avoid the trap of constituting tick-boxing exercises where certain aspects are overemphasized above other factors that contribute to well-being just as much. In the development of the indicators, government services should foster large consultation of care

professionals on one side and representatives of persons in need for care and support and persons with disabilities on the other.

Indicators must be linked to adequate control systems to make them a meaningful picture of the situation of long-term care quality and availability.

10. Prevention of elder abuse

Long-term care settings are naturally settings where the autonomy and independence of persons in need for care are challenged. Persons in need for care in all settings are vulnerable to all forms of abuse, including mistreatment or neglect. In many cases, their ability to report undue treatment is reduced either because of their condition, because it is made technically difficult to report to an independent person of trust with the ability to intervene, or because of the psychological effect of care dependency, where persons in need for care might not see an alternative to staying in an abusive situation, are abused by their only contact persons or persons of 'trust'.

Overburdening of formal and informal carers is an important source of abuse and neglect, which is why improving working conditions and supporting informal carers is crucial in reducing abusive settings. Nevertheless, preventing, raising awareness, reporting, and acting against abuse and perpetrators of abuse require safe and clear frameworks that explicitly address the issue.

Recommendation:

The EU Care Strategy should therefore contain the following elements to address the issue of elder abuse:

- Funding and calls to conduct further research on elder abuse in all care settings, to inform about the factors leading to abuse and practices to fight abuse
- Explicitly include neglect, chemical and physical restraints, and refusal of treatment as forms of abuse into the relevant definitions and make clear there is no place for such (non-)treatments in the EU
- Promote awareness, training, detection, and fight against elder abuse for all professions involved in long-term care as a key element of the Care Strategy
- Create public platforms for reporting elder abuse and equip them with sufficient resources to make them known and for them to effectively provide relief and support.
- Work on a formal recommendation on the topic of reducing abuse, such as based on the WeDO quality framework for long-term care services; ideally updating its provisions to further mainstream a human rights approach

11. Governance of the EU Care Strategy

The EU Care Strategy can only have an impact if it is effectively followed up by member States. To ensure that words are followed by actions, AGE proposes:

- To require **national implementation plans** to operationalize the provisions of the planned Council Recommendation
- To include **reporting requirements about access to long-term care and its socio-demographic determinants, as well as quality of long-term care and the state of social dialogue** in the sector into the annual Social Scoreboard published during the European Semester
- To **integrate the targets of the EU Care Strategy into the European Semester** and to issue regular recommendations to member States to improve their long-term care systems
- To hold a **regular review of the EU Care Strategy** and the attainment of its targets, for example by bi-annual dedicated meetings of the Social Protection Committee
- To explicitly require the **meaningful inclusion of representative organisations of persons with disabilities and of older persons** in the development, implementation and monitoring of national long-term care plans touching upon all the topics covered in this paper.

Annex: AGE Policy brief: Care must empower us throughout our lives

Annexed to this response you will find the recent AGE Policy Brief, setting out our vision for long-term care

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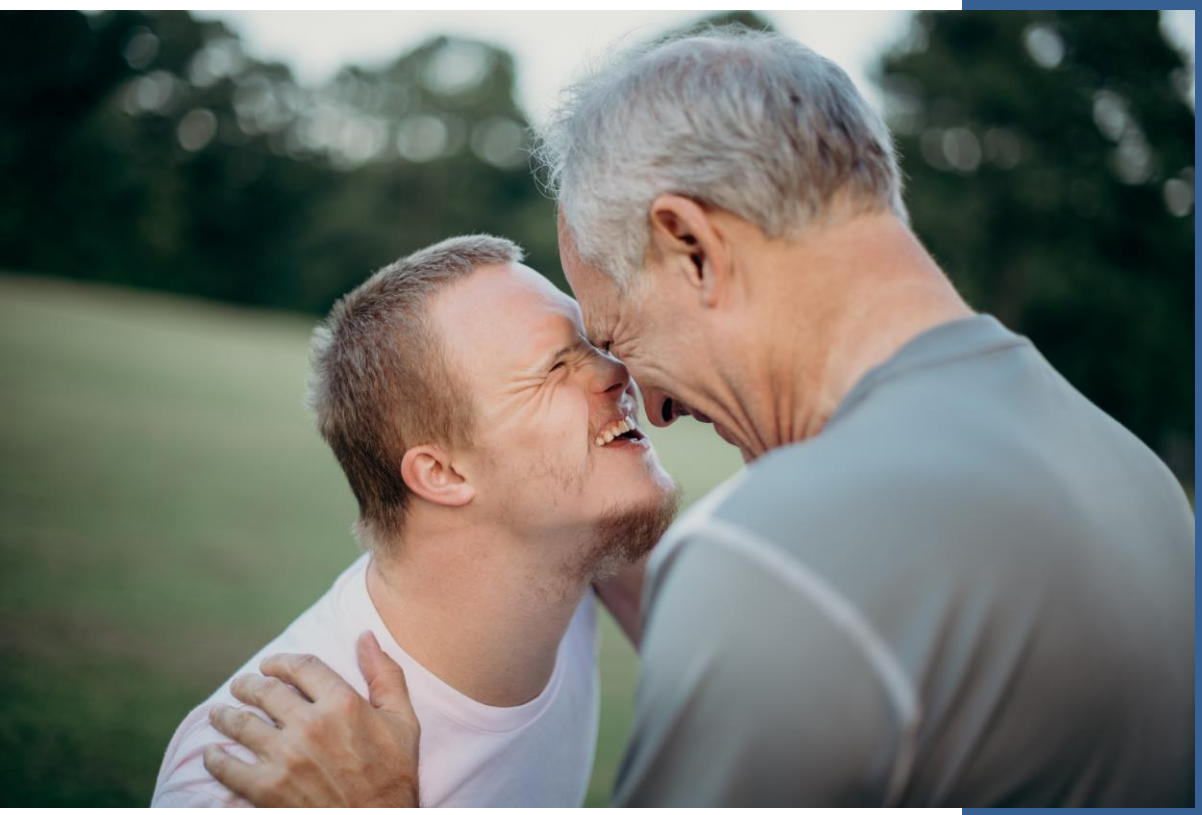
Care must empower us throughout our lives

Our views on change in care and support for older people



AGE Platform Europe

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Why this paper?

The impacts of the COVID-19 pandemic on older people in need of care have triggered more attention to the care sector and greater political interest. Yet, a financial focus on the costs of care and a tendency to think only of the short term are prevalent in policy responses.

What if we looked at care with new lenses? What if we looked at all the opportunities better care can offer? What if care was actually a great opportunity to seize?

Discussions need to embrace the lived realities of those in need of care, as well as their expectations and wishes. Thus, we need to discuss the future of care without avoiding the key questions:

What is our collective vision for care in older age?

What is the level of ambition we are willing to set collectively for the development of care policies and services?

The upcoming launch of a European Care Strategy in 2022 makes them more relevant than ever.

The aim of this policy brief is to put forward AGE Platform Europe's vision for change in care.

AGE members have their say:
Our Re-thinking Care process

Throughout 2021, we organised a series of four workshops with our members to discuss the change we want to see in care in Europe. The process involved 60 individuals from AGE member organisations in 18 European countries. Participants had a diversity of backgrounds and profiles: many are self-advocates who draw their views from their own personal experiences of ageing and care or past professional experiences, whereas others are working professionally in advocacy or in services for older people. They participated in at least one of the workshops, more often in several or all of them. Each workshop included group discussions addressing the key aspects of a process of change:

- Workshop 1 addressed the status quo in care: what AGE members like and dislike about care systems.
- Workshop 2 identified our shared vision for care: what care should help people achieve.
- Workshop 3 focused on the changes that are needed to achieve our vision of care: what steps will be needed in policies, services and at societal level to materialize change.
- Workshop 4 discussed the role of the advocacy work of organisations of older people: how we can play our part to make sure change happens.

This paper is the result of the views shared in these workshops. It also reflects the views shared by AGE members in our Task Force on Dignified Ageing, a working group that contributes to specifically shaping our work on care for older people.

As the voice of older people in Europe, **we call for care systems that empower each of us and support us to remain full members of society, no matter our age.**

This brief begins with an overview of the status quo in care today. It then presents AGE's vision of care, and the changes that are needed to materialise it. We end with a reflection on the role the European Care Strategy can play to trigger ambitious care reforms.

photo by Mihai Lazar on Unsplash

Care today: some **positive** aspects, many gaps

Europe's care systems have positive aspects we recognise, including committed care workers and dedicated informal carers, who play a key role in delivering support – often in difficult circumstances. Yet, older people with care and support needs still experience serious shortfalls that need to be addressed, including:

- **Ageism**[1,2,3] in care policies and services, which is a cross-cutting challenge and is intrinsically linked to **poor quality** driven by paternalistic practices, lack of involvement of older people in making decisions about their own care and the scarcity of rehabilitation and prevention as part of care systems and services.

- **Lack of or insufficient access**. According to 2014 data, only 1 in 3 older people with severe difficulties in activities of everyday life had access to care services at home in the EU; in 2019, 47.2% of people over 65 who needed help with their personal care and household activities reported a lack of services. Financial reasons are reportedly the main obstacle. The costs of care would put the majority of older people in the EU at risk of poverty if social protection did not intervene – and many experience poverty even after receiving financial support[4].

- **Organisational issues**, including lack of coordination between health and social care, staff shortages, insufficient funding and administrative barriers in accessing support [5,6].

Do you want to develop great care? Tackle ageism

Ageism is, according to the World Health Organization, "the stereotypes (how we think), prejudice (how we feel) and discrimination (how we act) towards others or oneself based on age". Ageism is far from anecdotal: 42 % of Europeans perceive discrimination due to old age (being over 55 years old) as "very" or "fairly" widespread in their country**Error! Bookmark not defined.**.

Ageism is pervasive in all aspects of older people's lives, and that includes care and support. It fuels a society where people have unequal worth depending on their age; thus, it explains why European political systems and societies have overlooked the situations of inequality experienced by older people in need of care and support and allowed these to exist for a long time. The lack of respect for older people's equal right to autonomy, physical and mental integrity, rehabilitation, independent living and choice has been widely documented during**Error! Bookmark not defined.** the COVID-19 pandemic, but it was previously already pervasive.

Ending ageism and affirming the full equality of everyone regardless of age or care needs is the precondition to fully and effectively address the structural shortcomings in care systems. Addressing the prejudices, stereotypes and discriminatory practices towards older people, in policymaking, in services and in societal attitudes, is key to imagining and implementing care systems

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[1] Our work on human rights and ageism is available in our website.
[2] Definition of ageism by the World Health Organization.
[3] "Shifting perceptions: towards a rights-based approach to ageing", report of the Fundamental Rights Agency (FRA), 2018
[4] "2021 Long-term care report", report by the European Union
[5] Amnesty International's work on the impacts of COVID-19 on care for older people in Spain, 2020
[6] "We have the same rights", research by ENNHRI (European Network of National Human Rights Institutions), 2017

For change to happen, a sustained long-term vision is essential

The greater political and societal focus on care because of the COVID-19 pandemic is an opportunity for wide debates around building better care systems and more equal societies. **Public debates on the reforms needed should be guided by a long-term vision, capable of inspiring action beyond short-term considerations.**

Yet, in the aftermath of the first wave of the COVID-19 pandemic, this is precisely what we have witnessed across Europe: a tendency to adopt sketchy policy responses driven by short-term emergencies. Some debates have emerged around the need to medicalise care homes or have focused only on ensuring preparedness for future pandemics[7]. Yet, long-term care systems in Europe do not need patches: they require systemic responses capable of addressing decades of inadequate care services and practices. They must be driven by a clear vision for the future.

Overall, the views of older people with care and support needs have most often been overlooked in debates. Yet, a rights-based approach to care and support involves, first and foremost, listening to older people and representative organisations and enabling a true societal debate to define the direction reforms should take.

Our members think of the future

In Spain, in 2020, the presidents of our members of the Spanish Confederation of Older People's Organisations (CEOMA) and the Democratic Union of Pensioners (UDP) endorsed an open manifesto calling for a new care model for older people. In *Ante la crisis de COVID-19: una oportunidad para un mundo mejor* (In the face of the COVID-19 crisis: an opportunity for a better world), signatories call for care to focus on home and to "eradicate the institutional model". The manifesto devotes one part specifically to the impacts of ageism and calls for action to fight it.

The Pensioners' Association of Austria (PVÖ) actively takes part in public debates around care reform. In their paper *Flege > Zukunft > Österreich!* (Care > Future > Austria!), PVÖ calls for the inclusion of care as a right enshrined in the Austrian constitution. They call on affordable and quality care for all, with a strong focus on prevention throughout individuals lives. The propose a vision that is holistic, and call for more support for home care and innovative housing solutions.

[7] Our analysis of the impacts of COVID-19 on older people's rights is available in our website, as is our views on recovery from the pandemic.

Credit : Tufayel Nayef in Unsplash

Care tomorrow: a solution that empowers

Care does not concern only older people. **Every individual needs care from the moment of birth** – and everyone should therefore enjoy the same rights in the care context at all stages. Differences in personal preferences and the kind and intensity of support people need do exist – and so within all age groups. Adopting a **life-course perspective** to care is therefore key to shape new care systems that enable everyone to enjoy the same rights[8].

What care should enable us do

It is high time to raise the level of our demands around care and support in older age so that equality becomes a reality for everyone.

We believe that care should support everyone to **participate, be included in society and continue doing the variety of things we like**, on an equal footing with others and at all stages of life. This involves having a voice and being free to make choices (self-determination). Care should respond to people's diverse needs and support people to live well, not just safer or in better health.

Care as a metaphorical tool according to participants to our Re-thinking Care process

If care services are capable of supporting people to do what they aspire to, they will ensure people are free, autonomous and independent – in one word, **empowered**. They will help people be part of our communities and able to continue contributing to them, as equal members of society whose voices count and are heard. Having access to care services is not the goal per se; empowering people to remain free, autonomous and independent is.

[8] Our contribution to the consultation on the Green Paper on Ageing in 2021 and our call for a new EU Age Equality Strategy build the case for a life-course approach in policies.

In sum,

Care empowers.

Care supports and enables inclusion and participation.

As we receive care we feel better.

Care supports us to remain included in the community, contribute to society and participate.

Getting there: the change we need to see

Moving from the current status quo to a Europe where care empowers will require **substantial change and continued efforts**. This change will involve new or reformed policies, services and societal attitudes, at local, regional, national and European levels.

The **matrix** on next page summarises our analysis: current status quo, identified key actions at all those levels and outcomes needed to achieve our vision of care. It is a dynamic **map** that can be used by stakeholders to:

- **Understand** the key components of a care system that empowers.
- **Steer progress** of care systems towards the realisation of our vision.
- **Plan** their own actions to make positive steps happen and steer their own progress.

This matrix is a living tool available for all stakeholders, which all can adapt and complete for their own use[9].

[9] If you wish to receive an editable format of this matrix to be able to adapt it to your own work and context, please contact AGE Platform Europe.

Status quo	Pathway		Vision
	Policies / services / societal changes	**The outcomes we need**	
Older people in need of care often lack **access** to services. Services may exist far from the community, only in institutional settings and/or be unaffordable.	Public and regular **monitoring of access** to services, across the territory	**Care is accessible.** It is available in the community and affordable for everyone, both in urban and in rural areas.	**Care empowers.** **Care supports and enables inclusion and participation.** **When we receive care we feel better. We can remain included in the community, contribute to society and participate.**
	Adequate public **funding and investments** for care services		
	Improvement of **working conditions** in care – including training – to increase the attractiveness of the sector and the quality of services		
	Development and improvement of **social protection** for care, including continuous monitoring of the costs of care for different needs and income levels after social protection		
	Specific policies and funding that enable the **transition to home and community-based care**		
	Quality monitoring systems that put the focus on qualitative dimensions and on the quality of life of people		
Social stigma around care needs and disability is prevalent. Ageism and ableism are widespread and have strong impacts on older people in need of care. Care for older people is not prioritized in policy or in society.	Education programmes to **combat ageism and ableism** in compulsory education and lifelong learning; also, in training for health and social care professionals	**Care needs and disability are socially accepted and prioritized.** There is a shift in mindsets to full social acceptance of care needs as inherent to all stages of the life cycle.	
	Public campaigns to end ageism and ableism		
Care services put safety and organisational needs above the wellbeing of people in need of care. They fail to respect people's needs and decisions.	Care professionals have a continuous, meaningful and timely **dialogue with people in need of care** so that services are organised around the care decisions expressed by them.	**Care services are person-centred.** They respect and contribute to realise people's aspirations and preferences. People receiving care are empowered and informed to make autonomous decisions around care and daily life.	
	Care services adapt to the changing needs of individuals.		
	Care regulations – laws, policies, protocols in services – **promote autonomy**; they make safety compatible with autonomy and independent living.		
Health and social care work in an uncoordinated manner. Budgets, means and objectives are defined in silos. People in need of care struggle to understand the care ecosystem.	People can access in timely manner **all care services** needed, ranging from health to social care and including palliative care	**Care is integrated.** All health and social care services and professionals coordinate smoothly. Informal carers are involved and supported.	
	A **care plan** to help health and social care services coordinate; they exchange information continuously		
	Informal carers to be involved in the design of the care plan. They receive psycho-social support and training		
	Health and social care authorities and all services work under a **shared strategic planning**: policies and budgets for health and social care are coordinated and pursue shared goals		
Care systems fail to prevent the deterioration of physical and mental capacities. Care practices sometimes aggravate such deterioration. Care policies target separately different age groups.	**Prevention and rehabilitation** are core topics of the curricula and missions of health and social care workers	**Care services ensure prevention and rehabilitation.** Care policies have a life-course approach.	
	Government programmes, funding schemes and service management pay specific attention to and create **incentives** for prevention and rehabilitation		
	Elimination of practices that aggravate physical and cognitive decline, including restrains and inadequate medication prescribing		
	Health and care policies integrate fully a **life-course approach**, thus demonstrating and enabling the prevention of care needs.		
Physical and digital environments are not accessible for everyone. They hinder equal participation and inclusion.	Policies and funding enable the adaptation of **housing, transportation and outdoor spaces** to make them accessible	**Communities are adapted to enable everyone to participate.** The physical and digital environments are accessible for everyone.	
	Accessibility criteria are enforced in all **digital services**		

The European Care Strategy: an opportunity to trigger change

The European Care Strategy, foreseen for 2022, can be an impactful tool to materialise many of the key changes identified above.

The Strategy can be a wake-up call to EU Member States to act and implement decisive changes in care. Whereas care is mainly a national competence, the EU can influence agendas and provide guidance on many of the policy, service-level and societal changes required.

An ambitious Strategy can produce positive impacts at two levels:

1) By putting forward an ambitious frame, data, evidence and a strong case for investments in care, the Strategy can trigger **a positive dynamic in which States converge upwards.** Peer reviewing, sharing of good practices and EU policy guidance can encourage States to **emulate** each other's practices and policies.
2) By including concrete flagships, objectives and a strong monitoring framework, it can **empower civil society and social partners** as key stakeholders to guide care reforms and steer progress.

What do we propose for the European Care Strategy?

The European Care Strategy must build a positive and compelling case for reform and investments in care, based on **a life-course approach** and the opportunities that better care systems offer to European societies. It should build on the approach to long-term care as a right, as proclaimed in the European Pilar of Social Rights.

- The Strategy should propose **indicators on access to professional care and support services** (measured in terms of met/unmet needs reported by people themselves), and also access targets. These should be disaggregated according to care settings, so as to monitor progress in improving access to home and community-based care, as mandated by principle 18 of the European Pillar of Social Rights.
- The Strategy should propose actions to build a shared understanding of quality of care and support across Europe. This should include a **European Quality Framework**, aligned with and linked to the European Quality Framework for social services of excellence for persons with disabilities announced for 2024 in the Strategy for the Rights of Persons with Disabilities 2021-2030.
- The EU should support and orientate long-term care reform in member states through the development of further **guidance, research and peer reviewing** on key aspects of care systems, including: the transition towards community-based care, social protection for care, integrated care, palliative and end-of-life care, the use of new technologies and support to informal carers.
- The Commission should develop a **repository of promising practices in long-term care** to inspire reforms and facilitate exchanges across Europe, with civil society involvement in both selection and evaluation.
- The Strategy should also launch a permanent **EU-level platform on care** composed of civil society-organisations to support and monitor implementation.

An ambitious EU Care Strategy should be anchored in the **European Pillar of Social Rights**[10]**.** This means that the Strategy should affirm **care of good quality as a social right** everyone should enjoy – and this includes implicitly the need to adopt a life-course perspective to care. In line with Pillar provisions, the Strategy should focus on making progress on access to home and community-based services.

It is indispensable that the Strategy is fully coherent with other EU policies, such as the **Strategy for the Rights of Persons with Disabilities 2021-2030**[11]**.** This involves cross-referencing the provisions on care, social services and independent living to ensure both Strategies have the same level of ambition. There can be no different standards: **everyone must enjoy the same standard of care and support regardless of their age and disability.**

Older people raise their voices for care reform

In Denmark, our member Ældre Sagen has launched the campaign *Værdig ældrepleje NU!* (Dignified care for older people NOW!). The online campaign, which includes a video, calls on coordinated professionals, support for socialization and participation and good personal care as key elements of dignified care.

The Slovenian Federation of Pensioners' Associations (ZDUS) has been actively involved in long-term care reform in the country. Influencing has included direct work with Parliament, including via the submission of critical comments and amendments to the reform under consideration.

The French Confederation of Retirees (CFR) has actively contributed to the reflections of the French government on care reform. Our member organisation has called on the care system to enable ageing at home, with an emphasis on prevention and the development of intermediary care settings. It calls on the meaningful involvement of older people in the reform process.

[10] Read our views on the implementation of the European Pillar of Social Rights.

[11] See our reaction to the Strategy for the Rights of Persons with Disabilities 2021-2030.

The way forward

We have before us the opportunity to learn from the shortfalls of care systems exposed by the COVID-19 pandemic. The crisis has proven the need to build a society where receiving support allows to unlock the potential of a growing part of the population.

Let's join forces to make it happen.

To know more, check out our resources:

- Our toolkit on dignity and wellbeing of older people in need of care offers evidence and key arguments for service providers and policymakers to change care systems.
- Our work on COVID-19 includes a paper on the impacts on the human rights of older people, a paper on the recovery from the pandemic. A new report will be issued early 2022.
- Our work on human rights in older age challenges ageism and puts forward proposals for a society for all ages.
- Our Ageing Equal campaign highlights the impacts of ageism on older people's lives and calls for action to ensure equality across the life-course.

For more information

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All pictures in the document: Unsplash.com

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